RICE UNIVERSITY

The Concept of Disability: A Philosophical Analysis

By

David Christopher Ralston

A THESIS SUBMITTED
IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE

Doctor of Philosophy

Approved, Thesis Committee

H. Tristram Engelhardt, Jr., Chair
Philosophy

George Sher, Herbert S. Autry Professor
Philosophy

Laurence B. McCullough, Adjunct Professor
Philosophy

D. Michael Lindsay, Professor
Sociology

HOUSTON, TEXAS
June, 2011

The Concept of Disability: A Philosophical Analysis

David Christopher Ralston
Department of Philosophy
Rice University

ABSTRACT

At the most general level, this project seeks to engage the question, "What is disability?" The conceptual exploration is undertaken against the background of the philosophical literature addressing the nature of disease, illness, and disability. This work contends that much of the literature bearing on the nature of disability fails to distinguish sufficiently between different *domains* of philosophical explanation and concern—ontological, non-moral normative, and moral normative, respectively. Specifically, this involves a failure to distinguish among (a) disputes regarding the proper ontological characterization of disability, particularly as expressed in medical-scientific explanations of the phenomenon; (b) disputes regarding the role of non-moral (aesthetic, epistemic, cultural) values or norms in the constitution of those explanations (i.e., non-moral normative concerns); and (c) disputes regarding moral and political considerations that shape the character of the social reality within which persons with disabilities live (i.e., moral normative concerns).

This work advances the thesis that disabilities, like diseases, are "natural," in the sense that they are not *mere* social constructions, but that values of various sorts nevertheless do enter into the identification of states of affairs as disability, and that the "disability" designation has important socio-cultural implications that are inevitably the subject of ongoing political negotiation. Specifically, this work argues that "disability" involves a complex interplay of ontological realities, non-moral normative, and moral normative considerations or values. This interplay is captured well by a "biopsychosocial" (BPS) approach to disability, one which incorporates these various considerations into a single account, involving an integration of different *levels of explanation* (biological, psychological, social) of the disability phenomenon. This work first develops the theoretical underpinnings and rationale for a BPS approach to disability (Chs. 1-3), then explores in detail some of the relevant ontological (Ch. 4), non-moral and moral normative (Ch. 5), and sociological and political (Ch. 6) considerations that enter into the identification of states of affairs as "disability," concluding (in Ch. 7) with a brief consideration of some of the study's implications for understanding the nature of disability, the future of disability studies and the disability rights movement, and the relationship between the disabled and the broader society.

ACKNOWLEDGEMENTS

I owe an enormous debt of gratitude to a number of persons, without whom this project would not have come to fruition. First of all, my advisor and mentor, Professor H. Tristram Engelhardt, Jr., was and continues to be an examplar of generosity, patience, and wise guidance. He has been helpful to me in so many ways, and I have learned so much from him. I am grateful beyond words.

To my other committee members—George Sher, Laurence B. McCullough, and D. Michael Lindsay—goes immense gratitude for their time and energies spent reading and providing very helpful feedback on earlier versions of this work. Each in his own way played a significant role in shaping the final product. Thanks to their input this work is much better than it otherwise would have been; of course, any remaining flaws are entirely my own responsibility.

The Department of Philosophy at Rice University has been an extraordinarily supportive and congenial environment in which to pursue graduate studies. I have learned and benefited greatly from the rich expertise of the department's faculty, as well as my interactions with fellow graduate students, and I am grateful for the many ways in which my time at Rice has helped me to grow and develop as a philosopher. Special thanks go to our department chair, Professor Steven G. Crowell, for his support and assistance at key points along the way; and to our wonder-working departmental coordinator, Minranda Robinson-Davis, without whom we all would be lost.

The writing of this dissertation was supported in part by a Summer Dissertation Writing Fellowship, awarded by the Office of Graduate and Postgraduate Studies at Rice University in the summer of 2010. This fellowship afforded me the opportunity to work full-time on the dissertation, and was crucial to my being able to complete the project. I would like to express my gratitude to the Philosophy Department for nominating me, as well as Dean Paula Sanders and Assistant Dean Celeste Boudreaux for making the fellowship possible.

To Fabrice Jotterand and Jeremy R. Garrett go thanks for fruitful professional collaboration on other projects, for very helpful advice in the final stretches of this project, and for encouragement along the way. Thanks also go to Dr. John Coverdale at Baylor College of Medicine and Dr. Eugene V. Boisaubin at the University of Texas Medical School for their professional support and assistance. Additionally, thanks go as well to Jean Ashmore, who in her role as Director of the Disability Support Services office at Rice University was a source of valuable information, practical assistance, friendship, and encouragement during my time at Rice.

I have been blessed with a number of very special friends during my time at Rice—including, (among others) Justin Ho, Brian and Adina Prince, Emilia Koivisto, Nissanka Wickremasinghe, Mike Karim, Wakaba Futamura, Christie Peebles, Luke Probst, Luke Chuang, Jared Day, Marx Mbonye, and Chirag Patel. Thanks to each of you for your support and encouragement along the way; I surely could not have made it this far without you!

To my family goes my undying love and gratitude—for their never-ending support and encouragement, and for believing in me and this project even when I could not see the proverbial "light at the end of the tunnel." During this last year especially, each of you helped me in ways too numerous to list here; please know that I will never forget and will be forever grateful.

Finally, and above all else, to the One in whom I live and breathe and have my being, thank You for being my strength and my life. *Soli Gloria Dei.*

TABLE OF CONTENTS

The Concept of Disability: A Philosophical Analysis

INTRODUCTION

I. BACKGROUND FOR THE STUDY

A. The Prevalence of Disabilities

An estimated 650 million persons worldwide has some form of disability, rendering disabled persons the world's largest "minority group" (UN Enable, n.d.).[1] This number continues to grow as a consequence of the confluence of aging populations, advances in medical care and technology, and overall population growth. At present, some 80% of persons with disabilities live in developing countries. Even in already-developed countries, however, the impact of disability can be significant: in those countries where life expectancy is greater than 70 years, individuals can expect to spend, on average, 8 of those years living with some form of disability—approximately 11.5 percent of their life spans. The impact of disability on income and employment is significant as well. In some countries, the unemployment rate among persons with disabilities is as high as 80%, a rate at least partly attributable to widespread negative assumptions concerning the ability of persons with disabilities to work. In the United States, according to a 2004 survey, approximately 35% of working-age persons with disabilities were actually working, compared with a 78% employment rate for those without disabilities. Of those survey respondents who had disabilities but were unemployed, two-thirds indicated that they had a desire to work but had been unable to find employment—and this despite the fact that, as a 2003 survey of employers found, in most cases (74%) disabled employees required no special facilities or accommodations at all, and for those who did require accommodations, the associated financial costs amounted to $500 or less (UN Enable, n.d.).

In 1991, the Institute of Medicine reported that disability-related costs to the United States amounted to more than $170 billion (IOM, 1991, p. 1). By 1997 that figure had risen to around $300 billion (more than 4% of the nation's gross domestic product at the time) [IOM, 1997, pp. vi-

[1] For the statistics cited in this first paragraph, along with a host of other disability-related statistics, see "Fact Sheet on Persons with Disabilities," compiled by UN Enable (n.d.) and available at http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf.

vii, 1]. In 1991, the number of Americans who had a physical or mental impairment significant enough to interfere with their "activities of daily living" (often referred to as ADLs) was in the neighborhood of 35 million. Of that number, approximately 9 million had impairments severe enough to make them unable to "work, attend school, or maintain a household" (IOM, 1991, p. 32). These two measures alone, the IOM committee concluded, rendered disability "the nation's largest health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large" (IOM, 1991, p. 32). Moreover, the demographic realities imposed by an increasingly-aging population, combined with the recent societal openness to addressing problems related to disability (as exemplified, for example, in the passage of the Americans with Disabilities Act of 1990), highlighted for the committee the urgency of its expressed Congressional mandate—namely, to explore and identify ways of preventing the occurrence and progression of potentially disabling conditions in the American population (IOM, 1991, pp. 32-34).

By 1997, the estimated number of Americans with some form of disability had grown to 49 million, or about one out of seven citizens (IOM, 1997, p. 2), and current estimates continue to range from 40-50 million (IOM, 2007, p. 1), depending on the definitions and measurement instruments used. Over the past two decades, there has been a notable increase among children of some potentially disabling health conditions, such as asthma, prematurity, autism, and obesity, accompanied by increases in "certain activity limitations that are not entirely explained by increased health and educational screening of children" (IOM, 2007, p. 66). Among adults 65 years of age or older, the 1990s saw an increase in the percentage of individuals with various forms of activity limitations (including "work limitations"), though as of 2007 that increase appeared to have "leveled off" somewhat. On the other hand, for as yet unexplained reasons, the older adult population has seen a decrease in the "prevalence of personal care and domestic activity limitations" during the past two decades (IOM, 2007, p. 66).

The numbers of individuals who are affected by disability are likely to increase dramatically in the coming decades, particularly as the so-called "baby boomer" generation

reaches the later stages of life, when the risk for disability is typically at its greatest. Indeed, as the Institute of Medicine put it in a 2007 report on *The Future of Disability in America,*

> [i]f one considers people who now have disabilities (at least one in seven Americans), people who are likely to develop disabilities in the future, and people who are or will be affected by the disabilities of family members and others close to them, then disability affects today or will affect tomorrow the lives of most Americans (IOM, 2007, p. 1).

Clearly, then, "disability is not a minority issue" (IOM, 2007, p. 1).

B. The Variability of Disability[2]

Disabilities are ineluctably diverse in their origins, types, manifestations, and effects upon different individuals; indeed, two or more individuals with the very same disability can be impacted in radically different ways and to very different extents. Etiologically, disabilities can be caused by birth defects that occur either during in-utero development or congenitally during the process of giving birth—both of which, in turn, can be the consequence of inadequate medical care at any stage during pregnancy, labor, or delivery. Disabilities can also be caused by environmental agents, diseases, traumas and accidents, including such things as land mines, wars, and other violent conflicts (JAF, 2009).

Broadly speaking, disabilities can be divided into two main categories: physical and intellectual. Physical disabilities, typically defined as "a condition that substantially limits one or more basic physical (mobility) activities, such as walking, climbing stairs, reaching, lifting, or carrying" (JAF, 2009), can include (among other conditions) polio, cerebral palsy, missing limbs, blindness/visual impairment, and deafness/hearing impairment (JAF, 2009).

Polio, a viral infection that attacks the spinal cord and the nerves that control bodily movement, can result in paralysis in affected parts of the body. The disease is the most common cause of physical disability in Africa and numerous other developing countries. Typically spread among children, polio frequently results in secondary disabling conditions such as contractures of joints (ankles, feet, hips, knees, elbows, wrists, and fingers) which prevent full bending of the

[2] The overview presented in this section is drawn from JAF (2009), though similar information could be found elsewhere.

affected joints. These contractures are usually the consequence of children crawling about on the ground because of the paralysis caused by polio.[3]

Missing limbs are frequently the result of environmental factors such as land mines, or due to accidental traumas or surgical amputations.

Cerebral palsy is a certain kind of disorder that results from damage to the brain. The term 'cerebral' indicates damage to portions of the brain associated with movement and posture. 'Palsy,' in turn, connotes "muscle weakness and inability to make voluntary movements" (JAF, 2009). Common characteristics of cerebral palsy include, but are not limited to, the following: muscle rigidity; poor muscle control; poor hand control; speech difficulties; paralysis of one side of the body (hemiplegia) or of all four limbs (quadriplegia); problems with coordination and/or balance; and, in about fifty percent of cases, mental retardation (JAF, 2009).

Blindness involves a total lack of vision; by contrast, "[a] person who is *visually impaired* may have some or very little vision, but needs assistance such as corrective lenses, a magnifier, or large print to employ vision in learning" (JAF, 2009, italics added). Three of the most common causes of blindness include trachoma, "dry eyes," and river blindness (JAF, 2009).

Deafness is defined as the inability to hear sound, "even with amplification"; those who are "hard of hearing," or *hearing impaired*, by contrast, "can still depend on the auditory channel (hearing) for learning and communicating; however, the hearing loss greatly affects their learning" (JAF, 2009). Deafness is commonly caused by hereditary (genetic) factors, premature birth, ear infections, and meningitis.

Another major class of disabilities is *intellectual disabilities.* This class includes *mental retardation* and *autism spectrum disorders.* Mental retardation is defined as

> a developmental disability that substantially limits a person's life skills. It is characterized by significantly sub-average intellectual function, existing concurrently with limitations in life skills such as: communication, self care, home living, social skills, academics, work, and recreation (JAF, 2009).

[3] For a brief personal account of the experience of post-polio syndrome, see Elshtain (2009).

Generally speaking, mental retardation can be traced to a number of prenatal, perinatal, and postnatal causal factors. Prenatal factors can include, among others, both genetic and nutritional factors (i.e., malnutrition during pregnancy). Perinatally, mental retardation can be caused by anoxia (oxygen deprivation during birth, typically caused by the position of the umbilical cord), breech birth, low birth weight, and/or premature birth. Postnatal causes of mental retardation can include childhood diseases (e.g., meningitis), as well as accidents and traumas (e.g., a blow to the head). Additionally, environmental factors such as poverty, malnourishment, toxins, and poor medical care in general can contribute causally to the development of mental retardation (JAF, 2009).

Mental retardation can be a prominent feature in a number of different syndromes, the most common of which is Down Syndrome (DS). DS comes in three different forms, each of which stems from a genetic chromosomal disorder. The most common variety of DS is called "trisomy-21," so named because every DNA cell in the affected person's body has an extra (21^{st}) chromosome. Persons with DS frequently exhibit physical traits such as having a smaller stature and head than their peers; having a short neck and "short, low-set ears"; as well as having slanted eyes and "a flat bridge on the nose" (JAF, 2009).

Finally, a number of conditions constitute the category of *autism spectrum disorders.* Autism, or Autistic Disorder, is a developmental disorder that principally affects three areas of function: (1) social interaction, (2) language skills, and (3) repetitive behaviors or interests. Onset of autistic symptoms typically occurs in children by the age of three. Significantly, the severity of symptoms and their impact on individual functioning can vary markedly from one person to another: "You may not see any symptoms of autism in a person who is high-functioning with a near 'genius' IQ. Another person with autism may be extremely low-functioning, with a low IQ, and may require a great deal of assistance with daily activities" (JAF, 2009). An individual who is diagnosed as autistic may also be diagnosed with one of the following additional conditions that fall under the broad heading of "autism spectrum disorders": (1) Pervasive Developmental Disorder (PDD), (2) Asperger's Syndrome, or (3) Childhood Disintegrative Disorder (CDD). A person with PDD "has some symptoms of autism but not enough to carry the classical diagnosis

of autism"; an individual with Asperger's Syndrome exhibits "autistic behaviors but [also] has good language skills"; and in the case of CDD, the child appears to develop normally for several years, but then "loses skills and develops autistic behaviors" (JAF, 2009).

In light of the foregoing, we can identify several key respects in which disabilities vary from one another. Disabilities vary from one another along at least four major dimensions: (1) the type of disability (e.g. sensory vs. cognitive); (2) the severity of disability (e.g. mild vs. severe); (3) the modality of function affected (e.g. hearing vs. sight); and (4) the primary etiology of disability (e.g. genetic vs. environmental).

Importantly, our aim here is decidedly *not* to provide an exhaustive taxonomy of the ways in which disabilities differ from one another; rather, the point here is simply to emphasize that speaking of "disability" generically is problematic at best. Consequently, any adequate account of disability should be sufficiently robust to allow for this variability among disabilities.

C. The Purpose of This Study

Building on a recognition of both the diversity among types of disabilities and the practical importance of disability to the future of American society, this work examines in detail some of the deeper theoretical issues posed by those practical realities. Though situated at the nexus of philosophy of medicine and social/political philosophy, as well as the field of Disability Studies, this project is principally a work in the philosophy of medicine. The aim is to develop a comprehensive philosophical analysis of a complex and multifaceted concept—the concept of disability—by drawing on and applying resources from the literature bearing on the notions of disease and illness, on the one hand, and extending those resources to a consideration of the nature of disability, on the other.

At the most general level, this project seeks to engage the question, "What is disability?" As it appears in the contemporary theoretical literature, this question is frequently framed in the context of highly contentious disputes about how best to conceptualize disability—in particular, whether the so-called "medical" or "social" model of disability is a more adequate account. On standard understandings of the models, the medical model identifies the *causal locus* of disability as being, in some sense, "in" the individual; the individual is "disabled" by some feature—a

"defect" (anatomical, physiological, etc.) or "loss" (amputations, etc.)—of her body.[4] By contrast, according to the social model, the *causal locus* of disability is to be found in social structures and practices that have the effect of excluding—and thereby disabling—those whose "anomalous"[5] physiological or cognitive constitutions render them different than the majority population. The debates over models grow fierce because they are taken to have direct and profound implications for (among other things) questions of social justice and public policy. Arguably, though, more heat than light has been generated in these disputes—so much so, in fact, that the models debate has recently been characterized as "increasingly sterile" (Shakespeare, Bickenbach, Pfeiffer, and Watson, 2003, p. 1105), perhaps even in a stalemate.

Against this backdrop, this project aims to take a fresh look at the question of what disability is—or, to put it differently, what it means to be disabled. The conceptual exploration will be undertaken against the background of the existing philosophical literature addressing the nature of disability, as well as the literature that focuses on the various concepts that have been framed regarding illness and disease. It will be argued that much of the literature bearing on the nature of disability fails to distinguish sufficiently between different *domains* of explanation and concern—ontological, non-moral normative, and moral normative, respectively. Specifically, this involves a failure to distinguish among (a) disputes regarding the proper ontological characterization of disability, particularly as expressed in medical-scientific explanations of the phenomenon; (b) disputes regarding the role of non-moral (aesthetic, epistemic, cultural) values or norms in the constitution of those explanations (i.e., non-moral normative concerns); and (c) disputes regarding moral and political considerations that shape the character of the social reality within which persons with disabilities live (i.e., moral normative concerns). The last of these encompasses various controversies about the proper socio-political constitution of the role of the disabled, if one can use such a phrase on analogy with what Talcott Parsons termed the "sick role" (Parsons, 1999)[6]—a controversial analogy in its own right.[7] The failure to attend to the

[4] See the subsection later in this Introduction, entitled "Two distinctions, two kinds of predication," for an important nuancing of this statement regarding identification of the "causal locus" of disability.

[5] To borrow Anita Silvers' terminology; see Silvers, 1998, 2009.

[6] See Turner, 1999. Following H.T. Engelhardt, Jr.'s summary, the "sick role" involves four key features: (1) a lack of responsibility for *being* in a state of illness (though moral blame may remain for *contributing* to being in a state of illness, e.g., through chronic smoking); (2) exemption from social duties; (3) a "therapeutic imperative"—that is, a duty to

distinction among the roles of medical-scientific explanatory accounts of disability (e.g., the anatomical, physiological, genetic, and other related causal factors that should be seen as central in the etiology of disability[8]), non-moral norms regarding proper function and form (e.g., the commonly-held belief that being blind or deaf is not as good as having sight or hearing[9]), and moral-political arguments regarding the proper social situation of the disabled (e.g., the various views regarding the obligation of society to respond to the needs of the disabled) has led to a widespread acceptance[10] of the view that (a) the "medical" and "social" models of disability are inherently incompatible, (b) one ought to criticize the "medical model" so as to support the "social model" of disability, and (c) the moral and political onus ought to be placed on society to adapt the environment to the needs of the disabled (e.g., building wheelchair-accessible entrances to buildings). Some of this literature even goes so far as to argue that it is *solely* the social environment (i.e. the "built" or "arranged" rather than naturally-occurring environment[11]) that is defective in engendering circumstances that render some persons disabled.[12]

The purpose of this study is not to argue that society bears no responsibility for accommodating the needs of persons with disabilities— indeed, as a "person with a disability" myself, I am sympathetic with many of the claims and objectives of what has come to be termed

---

seek out appropriate treatment from qualified individuals; and (4) a "defeasible assumption that sick people want to be treated." For more on the "sick role" and the "social performative" aspects of medical language, see H.T. Engelhardt, Jr., "The Languages of Medicalization," in *The Foundations of Bioethics* 2d ed. (New York and Oxford: Oxford UP, 1996), pp. 189-238.

[7] Indeed, one of the questions to be addressed in this study (see, in particular, Ch. 3) is whether or not there even *is* such a thing as a "disability role." See Barnes & Mercer (2003), pp. 3-4, for a discussion of the controversy over this issue.

[8] It should be acknowledged at the outset that this way of putting it is itself controversial, as some advocates of the "social model" of disability will argue that social factors, *in addition* to anatomic, physiological, and genetic factors, ought *also* to be seen as "central in the etiology of disability." For still others, social factors *alone* are etiologically central. The discussion of these issues throughout this work will seek to pay close attention to these sorts of nuances; for the moment, however, I set this dispute aside.

[9] This point encompasses questions such as whether the possession, or the lack/loss thereof, of "standard" sensory or mobility-related modalities such as sight, hearing, being able to walk without mechanical assistance, and so forth, is *intrinsically* good or bad, or only *contingently* so—that is, whether the lack (or loss) of such modalities is a disadvantage *simpliciter.* We shall attend to these questions explicitly in Chapter 5. For a recent discussion of these and related issues, see Cooper (2007) and Ralston & Ho (2007).

[10] Within the Disability Rights and Disability Studies communities, at least.

[11] These qualifications are important in light of the fact that one can speak of at least three distinct types of "environment": the naturally-occurring environment (e.g., the composition of the earth's atmosphere, the force of gravity, naturally-occurring topographical features, and the like); a "social" environment (constituted by social structures and practices); and the constructed (i.e., built) "physical" environment. Disability rights advocates, of course, typically take the physical (built/constructed) environment to be closely tied to, indeed an outgrowth of, the social environment. Thus, for example, they will account for the existence of certain "built" structures (e.g., those that pose barriers to persons with disabilities) on the basis of discriminatory, or at least unthinking, social structures and practices. For these reasons, they direct their critique principally at the "social" environment, and their proposed solutions are typically aimed at reformation of social structures and practices.

[12] For example: "...the social model of disability usefully reminds us that it is not the individual but the environment that is defective" (Silvers, 1998, p. 94).

the "Disability Rights movement."[13] Rather, this study will contend that the discussion of these matters has in many instances suffered from a fundamental confusion—namely, the aforementioned failure to distinguish between different domains of explanation—which confusion has resulted, in turn, in a conflation of causal explanatory accounts and social justice claims. As a consequence of this conflation, there has been a tendency to fail to distinguish between two types of questions: (1) how does one identify and distinguish social versus physical environmentally-dependent conditions[14]—along with the disease, illness, and disability, etc., that are attendant upon such conditions—on the one hand, and (2) how does one generate claim rights, on the other? A failure to acknowledge a distinction between these two types of questions can easily lead to the assumption that the identification of a socioenvironmentally-dependent condition (e.g., disability) *automatically* or *necessarily* entails the generation of a claim right. But this entailment does not follow logically; therefore, the move from (1) to (2) requires further argumentative support.

With this confusion operating in the background, it is often taken for granted that the medical model necessitates cure, repair, or compensation of the disabled, whereas the social model necessitates social reform to alleviate oppression and discrimination. This assumption, coupled with the further assumption that these two approaches to social justice are mutually exclusive, has led many theorists to conclude that the "medical" and "social" models are inherently incompatible with one another. The debate is then joined as to which model is superior and ought therefore to be adopted (over against the other). By contrast, this study will argue that this sort of talk about "models" is misguided to begin with. There may indeed be some respects in which the models are incompatible, but there are also respects in which they are, in fact,

[13] For a brief overview of the history of the disability rights movement, see Ralston & Ho, "Introduction: Philosophical Reflections on Disability," in D. C. Ralston & J. Ho, eds., *Philosophical Reflections on Disability* (Dordrecht, The Netherlands: Springer, 2009), pp. 1-16. For more extensive coverage, see Snyder, 2006; Asch & Wasserman, 2006; Barnes & Mercer, 2003; Barnes, Oliver, & Barton, 2002; Burgdorf, 2006; Peters, 2006; Scotch, 1989; Shakespeare, 2006; Shakespeare, Bickenbach, Pfeiffer, & Watson, 2006; and Snyder & Mitchell, 2006.

[14] For example, the fact that people tend to eat too much fast food at McDonald's might be viewed as a "social" environmental condition, whereas the epidemiological fact of a virus's spreading among a given population might be viewed as a "physical" environmental condition.

compatible with one another. However, neither model—at least in the form in which each is typically presented in the literature—is complete or adequate in itself.[15]

It is therefore essential, if any headway is to be made in understanding the nature of disability, that this fundamental confusion be clarified and rectified. The goal of this project is to dispel these confusions in the current conceptual debates about disability, and thereby to take up the challenge put forth by Lennart Nordenfelt some time ago, to "take part in the endeavor of construing a workable set of concepts in the area of disability and handicap"[16] (Nordenfelt, 1997, p. 621).

What is needed in this regard, it will be argued, is a deeper, more comprehensive analysis of the concept of disability, in terms of fundamental philosophical categories—specifically, ontology, non-moral normative value theory (including epistemology), and moral normative value theory.[17] In order to accomplish this, the study will motivate the project by analyzing and critiquing the "medical" and "social" models; the aim here will be to show ways in which these models are ultimately incomplete. This will motivate the remainder of the study, which will seek to move beyond the models debate altogether, by engaging in the task of developing a comprehensive analysis of disability in terms of the three major categories of philosophical inquiry mentioned above.

For theoretical underpinning, the work will draw upon George L. Engel's notion of a "biospychosocial model of disease," with a view toward expanding and applying the insights of Engel's work to a comprehensive philosophical analysis of disability. The important upshot will be that any adequate analysis of disability must take into account *all* of the relevant biological,

---

[15] Incidentally, this may help to explain why the disputes between social and medical model theorists are at once so vigorous yet intractable.

[16] As we will see, the term 'handicap' appears largely to be passing out of use these days, at least in the theoretical literature. We will consider the reasons for this later in this work.

[17] Generally speaking, ontology refers to the study of being; ontology investigates the nature of reality, asking questions about "what there is, e.g. material objects, minds, persons, universals, numbers, facts, etc." (Lacey, 1986b, p. 143). Epistemology, the study of knowledge, asks what we can know and how we can know it; this encompasses questions about the nature, types, objects, and origins of knowledge (Lacey, 1986a, p. 63). Value theory is "the branch of philosophy concerned with the nature of value and with what kinds of things have value"; broadly construed, value theory "is concerned with all forms of value, such as the aesthetic values of beauty and ugliness, the ethical values of right, wrong, obligation, virtue, and vice, and the epistemic values of justification and lack of justification" (Lemos, 1995, p. 830). As such, value theory encompasses both the "right" and the "good": what sorts of actions, qualities, and the like, are *right,* that is, (morally) *correct;* and what sorts of things are *valued* as being *good,* or *desirable*—and why. Moral value theory asks questions about the *right;* non-moral value theory asks questions about the *good,* and includes inquiries into such domains as aesthetic values, intellectual values, and the like. For general background on these three areas of inquiry, see Lacey, 1986 and Audi, 1995.

psychological, and social factors that play a role in rendering some persons "disabled." Only when one has developed such a comprehensive analysis of disability can one then go on to discuss (for example) matters of social justice and public policy—for only then will one have fully accounted for the relevant factors to which considerations of social justice and public policy must attend.

In this vein, chapter three puts forth a diagnosis of the problem with the current state of play in the literature: the reason why the medical versus social model debate has grown "sterile" (and may even be at an impasse) is that both approaches fail to take into account the full range of factors—biological, psychological, social, etc.—that account for a given state's being one of "disability." This study aims to correct that deficiency by developing a more adequate, comprehensive analysis of disability in terms of fundamental categories of philosophical inquiry.

In order to arrive at this more comprehensive and adequate analysis of the concept of disability, the study will consider pertinent questions raised in each of the following categories of philosophical inquiry: (1) ontology, (2) non-moral normative value theory (including epistemology), and (3) moral normative value theory. The relevant questions to ask in each of these areas can be identified by drawing on and applying resources from the literature bearing on the notions of health, disease, and illness—that is, the literature of the philosophy of medicine. Thus, for example, just as we can ask, with respect to diseases, whether they are "natural kinds" or (merely) instrumental classifications—the naturalism vs. non-naturalism debate in the philosophy of medicine—so we can also ask whether *disabilities* are anything more than (mere) instrumental classifications. More specifically, we can ask the following questions with respect to ascriptions of "disease" and/or "disability": what exactly are we predicating of an individual when we say that "X is diseased," or "X is disabled"? What kind of property attribution (e.g., an "intrinsic" or "extrinsic" property)[18] is being made when an individual is deemed to be "diseased" or "disabled"? And, with respect to what (ontological) standard are such attributions made—i.e., is there a "species-typical norm" with reference to which diseases and/or disabilities can be identified? These latter sets of questions will be taken up explicitly in chapter four.

---

[18] These terms will be defined shortly.

Moving to the non-moral normative domain, just as we might inquire regarding the extent to which values infect the identification of states of affairs as states of "disease," so too we might ask whether or not determinations of "disability" are similarly value-laden or value-neutral—reflecting the normativist/nonnormativist debate in the philosophy of medicine. Following on the answer to this question, we can inquire as to what sorts of values, if any, such determinations are laden. In chapter 5, we explore three key domains of non-moral normative values—namely, aesthetic, cultural, and epistemic—that enter into the identifications of states of affairs as disability. A crucial consideration in this context is that of the (non-moral) "goodness" or "badness"[19] of diseases or disabilities, and the factors that render such states good or bad. These sorts of questions are explored in the first part of chapter five.

Finally, the "moral normative" aspect of the value theory domain encompasses questions related to how we ought to *respond* to states of affairs identified as states of "disease," "illness," "disability," and so on. More specifically, we might ask the following question: what role do *moral normative* considerations play in our conceptual *understanding* of impairments and disabilities, on the one hand, and in judgments regarding appropriate social *responses* to conditions so labeled, on the other? A key question to be addressed in this context is that of whether or not disability is inherently "opportunity-limiting"—and, if so, what implications (if any) that might have for social and public policy (e.g., for choices related to how a society ought to structure the "dominant cooperative scheme" around which it organizes itself). These sorts of issues are addressed in the second part of Chapter 5.

In sum, this work aims to engage in a project of "philosophical therapy," that is, reframing the debate over the nature of disability by clarifying the discussion at its most fundamental conceptual level, with the aim of demonstrating that what initially appears to be a problem—namely, the apparent incompatibility of and resulting impasse between the medical and social models—actually turns out to be a benefit. That is to say, the models individually capture important dimensions of the complex phenomenon identified as 'disability,' but no single model

[19] The term 'bad' is, of course, notoriously vague—in saying "X is bad," do we mean that X is "bad" aesthetically, functionally, economically, etc.? Thus, we need to ask not only whether a given condition is considered "bad," but also in what *sense* (or, alternatively, on what *basis*) it is so considered.

tells us the whole story. Each illuminates important features of the phenomenon of disability, which features can then be analyzed in terms of ontology, non-moral normative value theory, and moral normative value theory. In this way, the models, though incomplete in themselves—indeed, precisely *because* of their lack of completeness—nevertheless push us to move *beyond* the "medical" vs. "social" model impasse toward a deeper, more comprehensive understanding of the nature of disability. This project thus seeks to develop a comprehensive analysis of the concept of disability, one that draws upon the insights of the "models debate" while also avoiding fundamental errors found in much of the current literature.

An important caveat is in order at this point. When discussing the social model of disability, and particularly if one is advancing a critique of the model, it is important to proceed carefully, for there turns out not to be a single, univocal sense of the term 'social model of disability.' Indeed, there are different versions of the model, ranging from the mild to what might be considered "radical."[20] This is an important point, for it may be that criticisms of one version of the social model will turn out to be ineffective against other versions. The diversity of views on these sorts of conceptual matters, even among disability scholars and activists themselves, is increasingly being recognized in the literature. Thus, for example, in a recently-published book entitled *Disability Rights and Wrongs* (2006), disability rights activist and scholar Tom Shakespeare aims his argument squarely at the "British social model of disability," which he characterizes as being significantly more radical than the model advanced by scholars in other countries. In fact, Shakespeare concludes that for a number of reasons "the British social model version of disability studies has come to a dead end"; by contrast, he says, "[i]t appears to me that disability scholars in other countries do not have the same problem, because they have adopted a less dogmatic version of the social approach to disability." Shakespeare's overall project, it must be emphasized, remains that of attempting "to show that it is possible to have a radical and progressive disability politics"; nevertheless, he thinks this can be done "without relying on a strong social model formulation of disability" (Shakespeare, 2006, p. 2).

[20] Shakespeare, for example, identifies the social model as just one member of "a family of social-contextual approaches to disability" (Shakespeare, 2006, p. 9). Later in this work (see Ch. 2), we will draw this distinction in terms of "constrained" versus "unconstrained" social model approaches.

Interestingly, this position represents a significant shift away from Shakespeare's earlier stance vis-à-vis the social model of disability. As Shakespeare explains, "I cannot claim to have been consistent in my writings on disability. At one time I was a critical friend of the social model, defending it against external attack...: I am now among those who argue that it should be abandoned" (Shakespeare, 2006, p. 5). Shakespeare's book is, of course, devoted in large part to explicating and defending his reasons for thinking that the social model (of the "British" variety) ought to be abandoned; we will not rehearse those reasons here. For present purposes, the point to be highlighted is that this change of position on Shakespeare's part illuminates the diversity and theoretical flux within the disability rights community itself, and that disability scholars have themselves begun to question the legitimacy of the social model, at least in certain of its forms. This, in turn, lends further warrant to the project in which this study is engaged—namely, that of moving beyond the models debate in search of a deeper, richer, and ultimately more philosophically satisfying account of the nature of disability.

If Shakespeare's project is at all representative of the direction in which the disability rights movement (or at least one of its major streams) is heading, then this would also bode well for the project in which this study is engaged. For, after identifying what he takes to be some of the central problems of the "British social model" approach to disability (to which we will return later), Shakespeare goes on to develop "an alternative account of disability, which is based on an interactional or relational understanding" (Shakespeare, 2006, p. 2). Disability, Shakespeare argues, "results from the interplay of individual and contextual factors. In other words, people are disabled by society *and* by their bodies" (Shakespeare, 2006, p. 2). Though not identical, Shakespeare's approach and the approach to be developed in this study will bear affinities to one another, particularly in their criticism of those approaches to disability which would seek to account for disability solely in terms of social structures and practices (i.e., a "radical" social model approach), and in their shared emphasis on the biopsychosocial variability of disability and its causes.

In sum, then, in much of what follows throughout this study, the principal "target" will be the more "extreme" or "radical" versions of the social model in particular, since advocates of such

theories tend to discount or even ignore important biological components of disability, to the point of implausibility. Still, if one is to assess the literature fairly, one must acknowledge that not all social model theorists are guilty of this charge, so the study will seek to proceed in such a way that these differences are acknowledged and taken into account.

II. PHILOSOPHICAL ISSUES IN THE ANALYSIS OF DISABILITY

Before embarking on the major project of this work, it will be helpful briefly to consider some of the central philosophical themes that recur repeatedly in the disability literature. Laying out this background here will help to avoid redundancy later on, as subsequent chapters will draw heavily on these themes.

A. Foundational Philosophical Questions

In an essay entitled "Philosophical Issues in the Definition and Social Response to Disability," David Wasserman (2001) identifies four foundational philosophical questions about impairment and disability.[21] Specifically, he identifies the following questions: (1) "How is philosophy relevant to disability policy?" (2) "What does it mean to classify a physical or mental condition as an impairment?" (3) "What does it mean to claim that an impairment is the cause or a cause of the personal and social limitations with which it is associated?" and (4) "What, if anything, is bad about impairments? Do impairments detract from well-being?"

As a way of setting the stage for subsequent discussion in this work, it will be helpful to review Wasserman's discussion of these questions. For present purposes, our aim will not be to actually answer them; instead, our aim at this point is simply to lay out an overview of some of the sorts of philosophical issues that are implicated in a discussion of impairment and disability, and to provide a sense of the complexity that would be entailed by a complete exploration of such issues. Some of these issues and questions will be picked up, in greater detail, at other places throughout this work; as such, this brief introductory overview will serve as a sort of "guide" to the territory to be explored elsewhere. Here, we will focus our attention exclusively on the first question listed above; the other three will be touched on elsewhere.

---

[21] In his essay, Wasserman speaks mostly of 'impairment,' using that term where other writers typically use 'disability.' As he explains, he speaks primarily in terms of "impairment" rather than "disability" in an effort to avoid begging any important conceptual questions about the latter. For his explanation of and justification for this terminological move, see Wasserman, 2001, p. 220. For present purposes, we will not distinguish sharply between the two terms. The impairment/disability distinction is discussed in greater detail in chapter 2.

There are, as Wasserman observes, a wide range of philosophical disciplines and sub-disciplines that are relevant to considerations of the nature of and proper social response to disability. Wasserman identifies at least seven such domains of inquiry: (1) philosophy of science, (2) philosophy of biology and medicine, (3) philosophy of action, (4) epistemology, (5) philosophy of language, (6) aesthetic and moral philosophy, and (7) social and political philosophy (Wasserman, 2001, pp. 220-222).

The *philosophy of science* is concerned with, among other things, understanding the notions of causation and explanation. What counts as a "good" explanation of a given phenomenon? How are "causes" to be identified and distinguished from one another? With respect to disability, important questions arise as to the relative contributions of biological, social, and environmental factors to disability, questions to which the philosophy of science is germane. In particular,

> [p]hilosophical accounts of the distinction between causes and conditions and of the relationship and ordering of different causal factors may be useful in evaluating medical, interactive, and social models of disability, with their apparently conflicting claims about the primary cause, or locus, of disability (Wasserman, 2001, p. 220).

As a sub-discipline of the philosophy of science, the *philosophy of medicine and biology* devotes considerable attention to exploration of fundamental conceptual notions such as health, disease, illness, normality, fitness, functioning, and the like, all of which form the backdrop against which concepts of disability are formulated (Wasserman, 2001, p. 220-221). Taken together, these notions have important implications for our conclusions about "the meaning, significance, and normative content of biological classifications and medical diagnoses" (Wasserman, 2001, pp. 220-221).

In the *philosophy of action*—which explores how agents are related, particularly though their actions, to the external world—important questions can be raised about the impact of impairments on the ability of agents to interact with their world, as well as the relationship between agents' "physical endowments" and their "efficacy" as agents. One particularly noteworthy line of inquiry within the philosophy of action, as it pertains to disability, is whether

impairments are best understood in terms of their impact on agents' ability (or lack thereof) to perform "basic" versus "nonbasic" actions (Wasserman, 2001, p. 221).[22] In this regard, Wasserman explains that

> [t]heories of basic action tend to treat impairments as having a presumptively negative impact on agents' efficacy and to underwrite a distinction between disability and handicap (or between activities and participation...) ... Critics of basic action tend to treat the agents' efficacy as more contingently related to their physical endowments (Wasserman, 2001, p. 220).

Epistemology, in its "concern for the importance and reliability of sense perception and the relationship of different sensory modalities," is obviously relevant to discussions of disability, especially to disputes concerning the meaning and significance of sensory impairments such as deafness, blindness, and so forth. The *philosophy of language*, in particular, "examines the completeness and comparability of different systems of communication, an examination relevant to the appraisal of the sign languages and tactile communication employed by blind and deaf people" (Wasserman, 2001, p. 221).

Aesthetic and moral philosophy raises crucial questions about the relationships between standard sensory and motor functions, on the one hand, and notions of well-being and social justice on the other. To what extent are sensory experiences commensurable with one another (if at all)? What impact does the enjoyment—or the lack—of particular sensory or motor functions have on individual well-being? What, if anything, is the relationship between the possession (or exercise) of standard sensory or motor functions, on the one hand, and notions such as humanity or personhood, on the other? Is there a minimum, "threshold" level of functioning that must be present (or achieved) in order to be considered "human" or a "person"? These and many other related questions fall under the ambit of this domain of philosophical inquiry (Wasserman, 2001, p. 220-222).

---

[22] A "basic action" is one "which is not performed by the performance of some other action," and a "generated action" is one that *is* performed by the performance of one or more basic actions (Nordenfelt, 1997, p. 611). An example of the former would be 'raising one's arm'; an example of the latter would be 'waving to someone by raising one's arm.' For a theory of health that relies heavily on action theory and a distinction between "basic" and "nonbasic" acts, see Nordenfelt (2000).

Finally, in the arena of *social and political philosophy*, we might ask what sorts of moral imperatives (if any) are generated by the presence or lack of standard sensory or motor functions. In particular, what implications do impairments have for questions of social justice? With respect to this latter question, Wasserman notes two divergent tendencies in the literature:

> ...recent social and political philosophy has taken two different and potentially conflicting approaches to justice that focus on different aspects of disability. The dominant approach understands justice primarily in distributive terms, in terms of the pattern of individual resources, opportunities, or welfare across society. This approach tends to treat impairments as functional limitations that may generate various distributive claims. A second approach understands justice primarily in terms of social structures and processes, in terms of relationships of power, privilege, and status among social groups. This approach tends to treat impairments as the markers of oppressed social groups and sees justice for impairments in terms of the elimination of oppressive and discriminatory attitudes and practices (Wasserman, 2001, p. 221).

These two ways of approaching disability, Wasserman says, find expression in general tendencies toward an "alignment of positions" (Wasserman, 2001, p. 221-222) vis-à-vis a variety of questions about the nature of disability; that is to say, given one's prior commitment to a particular way of viewing disability, one will typically tend to adopt one or another of two sets of stances regarding the nature of and appropriate social response to disability. Thus,

> philosophers who approach impairments as functional limitations tend to see the impairment classification as, at least in theory, value neutral and objective. While denying that that classification is based on value judgments, they also tend to regard normal functions as presumptively desirable and many, though not all, impairments as disadvantageous in causing various limitations and in denying or restricting valuable experiences or opportunities. They tend to see these disadvantages as exacerbated, but not created, by neglect and exclusion. They tend to favor medical correction or monetary compensation as the presumptive social response to disability.

> In contrast, philosophers who focus on impairment as stigma tend to regard the impairment classification as value laden and subjective. Moreover, they tend to reject the values they see as informing that classification. They deny that the conditions classified as impairments cause disadvantage or limit human flourishing and that people with those conditions have lives that are any less rich, complex, or satisfying than those classified as normal. They tend to regard the appropriate social response to disability as the transformation of the basic cultural, political, and economic structures of society, or more modestly, as the elimination of discriminatory attitudes and practices and their pervasive structural manifestations. They acknowledge that these changes may well affect the distribution of resources and the comparative advantage of individuals with impairments, but they do not have these as their primary purpose (Wasserman, 2001, pp. 221-222).

Of course, as Wasserman takes pains to point out, these "alignments of position" are by no means necessary or inevitable, nor are they mutually exclusive. One might, for example, consistently affirm an understanding of impairment as *both* a "source of functional limitation" *and* as stigma (or the marker thereof), and then proceed to advocate for environmental adaptation and/or social reform as principal responses to disability. One might adopt a "value-neutral" understanding of impairment, and then use that as a basis upon which to argue that "biological normality has only a contingent relationship to human flourishing and that the disadvantages associated with disability arise largely because social practices are tailored to normal human functioning" (Wasserman, 2001, p. 222). Similarly, even if one accepts the claim that certain impairments rule out the enjoyment of valuable experiences, that need not be taken to warrant the further conclusion that the overall value of one's life is thereby reduced by such impairments; instead, that premise may warrant the conclusion that "there is an indefinite variety of ways in which human lives can flourish" (Wasserman, 2001, p. 222).[23] Finally, "[a] focus on the functional significance of impairments is compatible with understanding disability as a poor fit between the individual and his or her environment,[24] such as an obsolete skill or membership in a very small linguistic or cultural minority" (Wasserman, 2001, p. 222). This latter view, Wasserman says,

[23] We will return to a consideration of these issues in chapter 5.
[24] Cf., for example, the ICF (2001) and IOM (1991, 1997) models, discussed in chapter 1.

"lends support to environmental modification over medical correction or monetary compensation as the presumptive response to disability" (Wasserman, 2001, p. 222). It is important to emphasize here that Wasserman is not in this context *endorsing* any of these specific views; his point—one that might seem patently obvious yet is all-too-often overlooked—is that there is no *necessary* or *simple* relationship between how one conceptualizes impairment, on the one hand, and what one argues is the appropriate social response to impairment, on the other. Instead, the possible relationships are *multiple* and *complex.* For this reason, this present work will forego a detailed consideration of particular social justice claims vis-à-vis the disabled; an adequate exploration of the relationship between disability and social justice would, as we suggested earlier, take us well beyond the scope of what can reasonably be accomplished here.

B. A Brief Discursus on Explanations

Since models of disability purport to offer an *explanation* of disability, one of our concerns here will be with the nature of explanation. An in-depth treatment of this subject is, of course, beyond the scope of this study; for present purposes, a general overview will suffice.

Broadly speaking, offering an "explanation" amounts to an attempt at "making something intelligible, or saying why certain things are as they are"; the term 'explanation' can also be used to refer to "the account used to do these things" (Lacey, 1986, p. 71). The "account" itself may be referred to as the *explanans,* while that which is being explained may be termed the *explanandum* (Lacey, 1986, p. 71).

In principle, an explanation could be offered for virtually anything—"a concept, a rule, the meaning of a word, the point of a chess move, the structure of a novel" (Kim, 1995, p. 256). In philosophical discourse, however, much attention has been focused on the nature of explanations of *events* and *human actions.* Explanations may seek to answer "how" questions (how did X happen?) or "why" questions (why did X happen?), or both—thus, explanations can be *causal* or *teleological,* or both. Additionally, an explanation may seek to perform an explicative function; on this usage, "*Explication,* when not simply a synonym for 'explanation', is the process whereby a hitherto imprecise notion is given a formal definition, and so made suitable for use in formal work"

(Lacey, 1986, p. 73). This may be accomplished by way of offering a *constitutive* account of a thing—the thing is explained by way of defining its constituent elements.

Whether an explanation purports to be causal or constitutive in terms of its explanatory *role*, we can distinguish among at least three *domains* of philosophical explanation—(1) ontological, (2) non-moral normative, and (3) moral normative, respectively. That is to say, a given explanation may seek to account for the phenomenon under investigation in terms of (primarily) ontological, non-moral normative, or moral normative factors. In the context of medicine, ontological explanations might focus on medical-scientific factors such as underlying biological or chemical processes;[25] non-moral normative factors might include, e.g., aesthetic values having to do with beauty, ideals of form and function, and so forth; and moral normative factors might include reference to broader social factors, including, e.g., the health care delivery system of a given society. The foregoing is not intended as an exhaustive list, and a given explanation might, of course, combine elements from more than one of these domains.

A good explanation will conform to a number of desiderata. In our present context, we can suggest a number of criteria for what might count as a "good" explanatory account of (or for) disability. First, it will attend to the differences among *domains* of explanation (i.e., ontological/medical-scientific, non-moral normative, moral normative). Second, it will include all the relevant features of the phenomenon it is seeking to explain (in this case, disability), and will exclude irrelevant features. And third, it will be sensitive to the diversity in kinds of disability, and how those differences might affect one's analysis of disability. Here again, this list is meant to be suggestive rather than exhaustive. The point is that given these desiderata—and, perhaps, others that might be devised in the course of future research—we can inquire, with respect to a particular "model" of disability, whether it satisfies these criteria; to the extent that a given model satisfies or fails to satisfy them, we may judge the model to be adequate or inadequate.

C. Two Distinct Questions, Two Kinds of Predication

[25] For our purposes, we can also refer to this type of explanation as a *medical-scientific* explanation; we will, therefore, sometimes use the label "ontological/medical-scientific" to refer to this type of explanation, and/or use the terms "ontological" and "medical-scientific" interchangeably.

When investigating the nature of disability, it is important to bear in mind an important distinction between two different but related questions that we may be asking: (1) What *is* disability? and (2) What is the *causal locus* of disability? The significance of this distinction can be illustrated by means of the following example. Social model theorists will often say something along the following lines: "Disability is the result of the failure of society to adapt to (or accommodate) the limitations of persons with disabilities." But this admits of more than one reading. On one reading, disability is *caused by* "the failure of society to adapt" to limitations. This is clearly a causal claim: society's failure to adapt *causes* disability; that is, certain persons have limitations, but those persons are *disabled* (only) when society fails to adapt to those limitations. On another reading, saying that disability "is the result of" society's failure to adapt can be read as a constitutive statement: disability *just is*, or is *constituted by,* the failure of society to adapt to the limitations of certain persons.[26] These two readings may yield different answers to the questions *what is disability* and *what causes disability*—and may, of course, also yield substantially different answers when considering subsequent questions having to do with social justice claims and related matters.

Models of disability thus serve two primary functions: (1) classification, answering the "What" question, and (2) explanation, answering the "Why" question (Silvers, 2009, p. 22). The first of these involves identifying *what disability is*—an identity question—and, typically, *who is eligible* to be considered disabled. Different models appeal to different properties to pick out who or what qualifies as "disabled"; the medical model, for example, will characterize disability in terms of "biological defect," whereas the social model will do so in terms of "social victimization" (Silvers, 2009, p. 22). The second function—explanation—seeks to explain why individuals are disabled (or, more precisely, "why they have the limitations associated with disability"; Silvers, 2009, p. 22). Typically, this involves offering both a causal account for why disability occurs and pointing to a preferred mode of intervention in that causal process. Thus, for the medical model, since disability is (primarily) caused by biological defect/dysfunction, "freeing individuals from biological dysfunction is the recommended approach to alleviate suffering from disability" (Silvers,

[26] Cf. the following definition advanced by some disability rights advocates: "Disability is the condition of being stigmatized and marginalized by society" (Eiseland, 1994, p. 24, quoted in Reinders, 2008, p. 47.

2009, p. 22). By contrast, given its emphasis on social oppression and discrimination as the (primary) causes of disability, the social model naturally "proposes that freeing disabled people from stigmatization and exclusion offers the most effective relief from suffering" (Silvers, 2009, p. 22).

One way to think of these issues is in terms of a distinction between properties that are taken to be "present in" versus "said of" an object.[27] (For reasons that will become clear in Chapter 1, we will sometimes refer to this either as (1) a distinction between "intrinsic" and "extrinsic," or "relational," *predications*; or (2) in terms of a distinction between "intrinsic" and "extrinsic/relational" *properties*). In the former case, the property in question is taken to be constitutive of the object; in the latter, the property is a category of judgment applied to the object. Applying this distinction to the text above, we note that in saying that models of disability seek to identify the casual locus of disability, this is ambiguous between whether the causal "source" (or "locus") is taken to be "present in" the individual with a disability (predication of a constitutive property), versus "said of" that individual (predication of judgment). Of course, in identifying an individual as "disabled," one might have *both* senses in mind; the two senses are not mutually exclusive.

Importantly, the second question above regarding the "(causal) locus" of disability actually encompasses three further, more precise questions—namely, (a) what is the specific *condition* to be explained? (b) what is the *pathogenic* cause of the condition in question? and (c) what is the *etiological* cause of the condition in question? For any given case of disability, we can distinguish between (1) the *condition* itself (e.g., paralysis, muscular dystrophy, etc.), (2) the underlying *pathogenic* cause (e.g. pathological, biological, or biochemical processes), and (3) the *etiological* cause (injury, disease, social practices/attitudes, etc.). Thus, for example, a case of paralysis (the condition itself) might be caused *pathogenically* by a severed spinal cord, but *etiologically* by having been hit by a truck while crossing the street (which, in turn, night perhaps have been the causal result of poor social planning). This latter cause, while not strictly "in" the individual, is nonetheless admissible in a "medical model" account. The primary point of contrast

[27] I am grateful to Laurence B. McCullough for alerting me (in personal conversation) to this distinction.

between the two models will be in what each would say regarding what it is that *disables* the individual in this case. For the medical model, what disables the individual in question is paralysis itself; a social model advocate, by contrast, might say that what "disables" a person with paralysis is discriminatory or unthinking social practices (e.g., a lack of curb cuts in sidewalks or ramps into buildings, thereby making wheelchair access difficult). The difference between the two models, in other words, revolves around what they take to be the central explanatory feature (or features) that accounts for a given individual's being "disabled." A medical model will tend to emphasize features in the *individual;* a social model will tend to emphasize features in the surrounding social *environment* (i.e., social structures and practices). As one might expect, medical and social model approaches tend also to differ in terms of their recommended "solutions" to the "problem" of disability—the former emphasizing medical treatment, the latter emphasizing social reform.

Returning now to our main point, namely, that there are two distinct questions that can be asked about disability—What *is* disability? What is the *causal locus* of disability?—it is worth pausing to underscore the larger significance of that distinction. The significance is to be found in the fact that a given "explanation" of disability may be seeking to answer only one of these two questions, or may be attempting to answer both questions simultaneously. Hence, in philosophically assessing a given explanation of disability, one must first ascertain which question(s) that explanation is intended to answer, and whether or not the explanation adequately answers the question(s). To fault an explanation for not answering a question it was never intended to answer in the first place is to place an unfair burden on that explanation. An ontological/medical-scientific explanation of disability, for example, may be seeking to answer only the first question, leaving the answer to the second question open; a moral normative explanation may focus on social *causes* of disability, leaving open the question of the precise *nature* of disability itself.

III. OVERVIEW OF THE STUDY

With the foregoing background in view, the study proceeds as follows. **Chapter 1** is concerned with laying out the theoretical background in terms of which discussions of disability take place in the contemporary literature. Specifically, this involves an examination of the key

conceptual components of which a number of representative models of disability are comprised, with a view toward identifying the ways in which those key terms are conceptualized in each case. Particular attention is paid to the kinds of predications (intrinsic vs. extrinsic) involved in the key conceptual terms that appear in each of the representative models.

Chapter 2 continues with the task of laying out the relevant theoretical background for our exploration of the concept of disability. We begin, first, with a reconsideration of three central conceptual terms that appear repeatedly throughout Chapter 1—namely, 'impairment,' 'disability,' and 'handicap'—with a view toward arriving at a clearer sense of the distinctions between them. Building on this exploration, we then go on to characterize, in a more general way, the *types* of models of disability exemplified in chapter 1, with a view toward identifying their respective commitments regarding the key conceptual terms/components. In this context, we discuss and offer brief critical analysis of the major approaches to modeling disability—the "moral," "medical" and "social" model approaches, respectively. The chapter concludes with an argument to the conclusion that we need a deeper, more adequate theoretical/philosophical framework that will enable us to move beyond the so-called "medical-versus-social-model impasse." Chapter 3 is devoted to the actual development of such a framework.

Chapter 3 is concerned with demonstrating that the resources of the philosophy of medicine can be useful in moving us beyond the "medical vs. social model" impasse, and in providing us with a fuller, more comprehensive picture of the nature of disability. This is accomplished by developing an argument to the conclusion that there is a significant parallel between questions raised when considering the nature of disease and illness, on the one hand, and disability on the other. In both domains, it will turn out, we can raise questions of an ontological, non-moral normative, and moral normative variety. This discussion serves to motivate the remainder of the study, which is engaged in the constructive project of developing a comprehensive analysis of disability in terms of these categories of philosophical inquiry.

As a way of deepening and extending the analogy between disease and disability, this third chapter explicates George L. Engel's "biopsychosocial model of disease," identifies key elements of that theory, and sketches how those elements might apply to the concept of

disability. This part of chapter three thus constitutes an argument to the conclusion that Engel's "biopsychosocial model" provides a useful framework within which to think about the nature of disability, and thereby serves to motivate the use of this approach in the context of the study's larger project of developing a comprehensive analysis of disability.

Chapter 4 focuses on the following two ontological questions: (1) With respect to what (ontological) standard are disability attributions made—is there a "species-typical norm" with reference to which disabilities can be identified? That is, what is the relationship between "disability" and "normalcy"? and (2) What kind of property attribution (e.g., intrinsic vs. extrinsic) is being made when an individual is described as being "disabled"? That is, what does it mean to characterize an individual as "disabled"?

These discussions take place against the theoretical backdrop of the naturalism/non-naturalism and normativism/non-normativism debates in the philosophy of medicine. After setting forth the general contours of these debates, Chapter 4 develops an argument for a "weak naturalism/weak normativism" position vis-à-vis these matters. Among other things, this sort of position involves the claim, at minimum, that there is at least *some* ingression of normative values into determinations of disease and illness. From there, we argue in Chapter 4 that a similar claim can be made with respect to determinations of disability.

Chapter 5 follows up on this argument by asking the question: given that there is at least some ingression of normative values into determinations of disease, illness, and disability, with what sorts of values are such determinations laden? In the first part of Chapter 5, we explore three central domains of non-moral normative values that enter into these sorts of identifications—namely, aesthetic, cultural, and epistemic values. In the second part of Chapter 5, we explore the question of what role moral normative considerations play in our conceptual understanding of impairments and disabilities, on the one hand, and in judgments regarding appropriate social responses to conditions so labeled, on the other. Finally, the intertwining of these major domains of moral and non-moral normative values in the identification of states of affairs as ones of "impairment" and/or "disability" is illustrated in this chapter by an exploration of

the "deafness debate," along with a consideration of the extent to which the issues involved in that debate generalize to other forms of disability.

In **Chapter 6,** we draw on relevant sociological literature to explore some of the sociological and political dimensions of disputes concerning the nature and proper conceptualization of the concept of disability. In the first half of Chapter 6, we discuss some pertinent sociological research on "minorities" and group identity, with a focus on two key questions—namely, (1) *why* do groups seek recognized "minority" status, and (2) *how* do groups seek recognized "minority" status? These discussion set the stage for the second half of Chapter 6, which engages in an extended discussion of the relationship between disability and stigma, with a particular view toward inoculating the BPS approach advocated in this work against a potentially serious objection—namely, that by incorporating the insights of the medical model, rather than *rejecting* it outright, the BPS approach effectively *stigmatizes* the disabled.

In **Chapter 7**, we (1) consider briefly how the different levels of explanation in a BPS account "fit together"; and then (2) consider some of the implications of this study for (a) our understanding of the nature of disability, (b) the future of disability studies and the disability rights movement, and (c) the relationship between the disabled and the broader society.

By way of further delimiting the scope of the present work, it should be noted that our focus will be primarily on the complex interplay of *ontological* and *non-moral normative* realities in addressing the "what" and the "why" questions about disability. For purposes of the present work, we will for the most part bracket a detailed exploration of distinctively *moral normative* considerations. The main rationale for this is that moral normative considerations have primarily to do with questions about the appropriate *social response* to disability. Our principal aim in *this* work, however, is to get a handle on the *prior* conceptual questions of what disability is and what causes disability. A fully adequate exploration of moral normative considerations related to disability would require a consideration of a whole host of issues and questions—including such topics as theories of equality and justice, the relationship between disability and theories of equality/justice, the relationship between disability and "opportunity" (e.g., is disability inherently opportunity-limiting?), and so forth—that would take us well beyond the scope of what can

reasonably be addressed in a single work. For that reason, we will save a detailed consideration of moral normative issues related to disability for a subsequent work. However, as noted above, we will touch on some of these issues in the second half of chapter 5. Moreover, we will have occasion throughout this work—especially in the concluding chapter—to suggest some potential implications of our findings here for that larger area of further inquiry, though we will not be concerned in this work to develop or defend those suggestions in any detailed or exhaustive fashion. In short, the primary focus of the present work will be on the narrow conceptual questions of what disability *is* and what *causes* disability—the chief motivation for that focus being the thought that those prior conceptual matters form the crucial theoretical background against which (or in terms of which) *any* discussion of social justice as it relates to disability must take place. In other words, it makes little sense to talk about how we ought as a society to *respond* to disability, if we do not first have a good grasp of what it is that we are responding to and how it came about. These, then, are the major issues to which this work will attend.

Chapter 1

THE CONCEPT OF DISABILITY: MODELS OF DISABILITY (I)—ANALYSIS

I. INTRODUCTION TO CHAPTERS 1-2

Chapters 1 and 2 are devoted to laying out the theoretical machinery requisite for subsequent discussion of the specific questions to be taken up in the remainder of the work, in view of the overarching goal of bringing the resources of the philosophy of medicine to bear on the question of the nature and conceptualization of disability. With that goal in mind, Chapters 1 and 2 engage in an extended analysis of the basic conceptual components of which some representative models of disability are comprised. The upshot of Chapter 1 is a mapping of the commitments that each of these representative models makes with respect to each of the central terms, where the conceptual components are analyzed in terms of the types of predication they make regarding their respective referents.

The first part of Chapter 2 focuses our analytical attention on the three central terms—'impairment,' 'disability,' 'handicap'—that recur repeatedly in the disability literature. In that context, we consider the distinctions between impairment and disability, on the one hand, and between disability and handicap, on the other—two key distinctions that play a prominent role in the theoretical literature. In the remainder of Chapter 2, we move on to consider more generally three major *types of approaches* to modeling disability—namely, the "moral-model" approach, the "medical-model" approach, and the "social-model" approach—again with a view toward understanding their respective commitments regarding the three central terms (impairment, disability, and handicap) examined earlier in the chapter.

Collectively, the work done in Chapters 1-2 sets the stage for developing, in Chapter 3, a positive philosophical framework within which to analyze the concept of disability. In particular, the extended focus on the types of predication involved in representative models of disability provides us with the resources to support the claim, made later in this work, that any adequate account of disability *must* include reference to *both* "internal" *and* "external" factors.

II. MODELS OF DISABILITY: A DETAILED ANALYSIS

Our investigations in this chapter and the next will lead us into a consideration of (1) several representative *models* of disability, (2) the distinct *conceptual components* that comprise the models, and (3) some *definitions* of disability derived from these models. (The findings of these explorations are summarized in Tables 1.2 and 1.3., at the end of the chapter.) These elements are related in the following way: individual conceptual components are combined in various ways to form models, from which specific definitions of disability are derived. Models of disability, in turn, offer either a *causal explanation* for, or a *constitutive explanation* of, disability—or both.

We *begin* with an examination of specific models of disability and their constituent conceptual components for primarily strategic reasons. Approaching our examination in this way affords us a convenient entrée into the larger project to which this work is dedicated; by starting with specific models and their conceptual components, we may hope to glean a "rough and ready" sense of the "state of play" in the disability literature, as well as a working idea of what is meant by such ubiquitous terms as 'impairment,' 'disability,' 'handicap,' and the like. The strategy, in other words, is essentially a "bottom-up" rather than "top-down" one: by looking at different ways in which key terms are *used* in the contemporary literature, we hope to discern some clues as to what those terms might *mean,* and in this way to launch the process of engaging in a comprehensive philosophical analysis of the concept of disability.

A. What are Models?

Models are "systematic organizations of conceptual elements" that aim to tell us how those conceptual elements are related to one another (Altman, 2001, p. 111). According to Franfort-Nachmias and Nachmias, models perform three primary functions: (1) they identify "certain aspects of the real world as being relevant to the problem under investigation," (2) they make explicit the "significant relationships" between those identified aspects, and (3) they make it possible to formulate "empirically testable propositions regarding the nature of these relationships" (Franfort-Nachmias & Nachmias, 1992, p. 44, quoted in Altman, 2001, p. 112). Similarly, Silvers (2009) identifies two distinct functions that models serve: (1) classification,

answering the "What" question (e.g., "what is disability?"), and (2) explanation, answering the "Why" question (e.g., "what is the cause of disability?") (Silvers, 2009, p. 22).

The importance of models of disability is, in part, a function of the uses to which they can be put (Shakespeare et al., 2006, pp. 1101-1102). In the context of public policy, models may be employed for purposes of distinguishing between those who qualify as "disabled" and those who do not, which in turn may serve as the basis for determining eligibility for welfare or other social benefits. In the clinical and rehabilitative settings, models of disability may be utilized as part of the process of assessing the relative effectiveness of different treatments or therapeutic interventions. Social scientists may employ models for purposes of clarifying "the causes of disadvantage," analyzing the relationships between individuals and their social/cultural environments, and setting priorities for needed societal changes. Finally, disabled people may themselves use models of disability in the process of gaining understanding of their world and explaining the disability experience, which in turn may have practical upshots for their self-identity and/or for political action (Shakespeare et al., 2006, pp. 1101- 1102).

Models thus are developed with particular purposes in mind, and the final product put forth by the modelers reflects those purposes. For example, Saad Nagi (1965, 1969, 1991) was a sociologist by training, and was therefore concerned primarily with sociological explanation. By contrast, in developing its models of disability—the ICIDH (1980) and the ICF (2001), respectively—the World Health Organization was interested in developing a classification scheme that would provide exclusive, non-overlapping categories that would be of use to medical and rehabilitative professionals in the clinical setting[1] (Altman, 2001, pp. 111-112).

B. Some Prominent Models of Disability, Their Key Conceptual Components, and the Relationships Between Those Components

In an essay entitled "Disability Definitions, Models, Classification Schemes, and Applications," Barbara Altman (2001) provides a helpful overview of some of the most prominent models of disability that have been proposed; her discussion includes a detailed analysis of the

[1] The ICIDH and ICF were also explicitly designed to be both analogous and complementary to the *International Classification of Diseases* (the current version is the ICD-10; see WHO, 1990), which in turn was intended to be of use, among other things, in classifying various treatments for payment purposes.

constituent conceptual components of each model, followed by a consideration of the similarities and dissimilarities in the meanings given to those conceptual components in the respective models.

For purposes of inter-model comparison, Altman identifies the distinct conceptual components of which each of the models is comprised, labeling them as "first components," "second components, "third components," "fourth components," and "fifth components," respectively. This is a useful way of approaching the subject, for, as will become clear momentarily, different models of disability frequently "use the same terminology but ascribe a different meaning to the terms" (Altman, 2001, p. 101). Hence, having a template in terms of which to analyze the different meanings of terms that might, on first blush, appear to be the same, is a helpful way of keeping track of the different senses of the various terms.

Altman's analysis focuses on the following representative models of disability: (1) the Nagi model (Nagi, 1965, 1969, 1991); (2) the Verbrugge and Jette model (1994); (3) the two versions of the World Health Organization's model: the *International Classification of Impairment, Disability, and Handicap* [ICIDH] (WHO, 1980), and the *International Classification of Functioning, Disability, and Health* [ICF] (WHO, 2001)—sometimes referred to as the "ICIDH-1" and "ICIDH-2," respectively;[2] (4) the two Institute of Medicine models ("IOM-1" and "IOM-2") [Pope and Tarlov, 1991; Brandt and Pope, 1997]; and (5) the social model as developed by disability theorists in Great Britain, such as Abberly (1987) and Oliver (1990, 1993, 1996).[3] These models are of particular importance because they have been especially influential in the disability literature and/or in various public policy contexts. Thus, for example, the Nagi model has served as the theoretical basis for most U.S. disability law and social policy, including (most prominently) the Americans with Disabilities Act (1990), as well as for statistical purposes in the United Nations and European Union contexts, and in numerous other settings (Shakespeare, Bickenbach, Pfeiffer, & Watson, 2006, p. 1102).

---

[2] I will, accordingly, sometimes use the "ICIDH-1" and "ICIDH-2" labels to distinguish between the two models, in lieu of the "ICICH" vs. "ICF" pairing.

[3] The discussion here relies heavily on, and follows the order of discussion in, Altman (2001).

As an aid to the reader, it will be helpful to present, at the outset, a slightly-modified version of a chart that Altman provides in her essay, in order to highlight the respective relationships between the individual conceptual components that feature in the models of disability under consideration here. Subsequent discussion will follow closely the material presented in this chart.

Table 1.1 Names and Relative Locations of Conceptual Components in Models of Disability Discussed in this Chapter
(Source: Adapted from Altman, 2001, p. 103, Table 3.1)

Model	***1st component***	***2nd component***	***3rd com-ponent***	***4th component***	***5th component***
Nagi (1965)	Pathology	Impairment	Functional limitation	Disability	-----
IOM-1 (1991)	Pathology	Impairment	Functional limitation	Disability	-----
IOM-2 (1997)	Pathology	Impairment	Functional limitation	Disability	-----
Verbrugge/Jette (1994)	Pathology/disease	Impairment	Functional limitation	Disability	-----
ICIDH (1980)	Disease and disorders	Impairment	Disability	Handicap	-----
ICF/ICIDH-2 * (2001)	Health context	Body function/body structures/ impairment	Activity/ activity limitation	Participation/ participation limitation	Context: environmental & personal
Social model	Impairment	Disability	-----	-----	-----

* = TERMINOLOGICAL NOTE: The ICIDH-2 represents the World Health Organization's 1999 revision of the ICIDH-1. The revision process was subsequently finalized and the ultimate result published by the WHO as the *International Classification of Functioning, Disability, and Health* [ICF] in 2001. Consequently, the disability literature now refers to the ICF (2001) rather than to the ICIDH-2 (1999), and the ICF is considered the "current" WHO model of disability.

The chart identifies the key terms, or conceptual components, that are employed by each of the models under consideration, and shows the position occupied by each conceptual component (a) within each model, and (b) relative to the other models. Thus, for example, where the Nagi, IOM-1, and IOM-2 models all begin with "pathology" as their first term, the ICIDH-1 speaks of "disease and disorders," the ICF/ICIDH-2 speaks of "health context," and the social model speaks of "impairment." Where the ICIDH speaks of a simple impairment-disability-handicap trichotomy, the ICF/ICIDH-2 further specifies these notions in terms of "impairment" of body functions or structures, on the one hand, and "limitations" of either "activity" or "participation," on the other. That is, the term 'disability' is further specified in terms of a distinction between "activity limitations" and "participation limitations," while the term 'handicap' drops out of the picture

altogether. The ICF/ICIDH-2 is also unique in explicitly specifying "contextual factors" (personal and environmental) as conceptual components in the model.

As we will see, despite the similarity in *terms* employed by the major models of disability, the *meanings* of those terms can vary significantly from model to model. More precisely, the models can vary in terms of both the *reference* of and/or the *sense* given to each of the individual conceptual components. That is to say, while the models employ the same or very similar terms, those terms are often *conceptualized* in very different ways. It will be helpful for our purposes, then, to see if we can generalize regarding the different ways in which the central terms are typically conceptualized in the literature—to which task we will turn in Chapter 2,

In the Introduction to this work we set forth an important distinction between two types of predication—namely, (1) predication of intrinsic constitutive properties, and (2) predication of judgment. As we explained in that context, these are two different ways of making property attributions about an object, involving statements to the effect that a property is either "present in" or "said of" a given object. In the former case, the property in question is taken to be constitutive of the object; in the latter, the property is a category of judgment applied to the object.

In that earlier discussion I suggested that this distinction can be useful for disambiguating the ways in which the different models of disability attempt to identify the casual locus of disability—that is, to answer the "Why?" question. I now want to suggest that this same distinction can also be helpful, at the micro level, in disambiguating the different senses and referents of the key conceptual components employed in each of the respective models. Thus, for example, we can ask whether a given model uses the term 'disability' to refer to an intrinsic constitutive property of an individual (something that is "present in" the individual) or, instead, refers to a judgment made about an individual (something "said of" the individual). Similar questions can be raised regarding the other conceptual terms ('impairment', 'handicap', etc.) as well.

With that in mind, after setting forth a geography of the central terms employed by each model, we will proceed to specify, for each of these terms, what type of predication is involved in each case. (The results of this investigation are summarized in Table 1.2, below.) This will pay dividends throughout this work, for, as will become apparent, this initial survey of these

representative models will surface important conceptual and philosophical themes to which we will return repeatedly throughout this work. For reasons that will become apparent later in this work, we will also be concerned to highlight the role of *norms* and notions of *normativity* in the models. That is, we will be concerned to point out, where relevant, the infiltration of normative concerns into the characterization of the key conceptual terms of which the representative models are comprised.

With this overview as a starting point, we now proceed to a detailed analysis of the distinct conceptual components employed by each of the respective models. Since models are frequently articulated in response to difficulties posed for earlier models, our discussion will proceed in rough chronological order, from the earliest to the most recently-formulated models.

1. Nagi model (1965)

a. Background/Overview

Saad Nagi's model was developed in the general context of rehabilitation, and specifically in the context of vocational rehabilitation. Occasioned by a conference (termed the "Carmel Conference") convened by the U.S. Vocational Rehabilitation Administration (VRA), the model was intended as an aid to rehabilitation professionals in understanding disability and related concepts (Sussman, 1965).

b. Conceptual components

In approaching his discussion of disability, Nagi noted a widespread "inconsistency" in the then-current literature on impairment, disability, handicap, illness, and the like—specifically, in their various (and often conflicting) uses of those terms—resulting, in his words, in a state of "semantic and conceptual confusion" (Nagi, 1965, pp. 100-101). In an effort to ameliorate this difficulty and to advance the discussion of these notions, Nagi set out to develop a clear conceptual framework that would differentiate adequately among these "overlapping but analytically separable" concepts (Nagi, 1965, pp. 100-101).

To that end, Nagi (1965) lays out explicit definitions for the four key terms of which his conceptual framework is composed—namely, *active pathology, impairments, functional limitations,* and *disability.* In the course of his discussion, he also offers an explicit definition of

sickness (or *illness*). These definitions, as expressed in his 1965 article (and clarified in subsequent publications), are as follows:

(1) **df. 'active pathology' =** "First is a state of mobilization of the body's defenses and coping mechanisms—a condition that may result from infection, metabolic imbalances, traumatic injury, or other etiology and is commonly referred to as *active pathology* or disease process" (Nagi, 1965, p. 101).

(2) **df. 'impairments'** = "Second are anatomical and/or physiological abnormalities and losses, which will be labeled *impairments*.... every disease involves an impairment, but not every impairment involves a disease"[4] (Nagi, 1965, pp. 101-102). For Nagi, "impairment" can include conditions associated with pathology (e.g., an amputated limb due to an infection) as well as conditions not associated with pathology, as, e.g., in congenital deformities (Altman, 2001, p. 104, citing Nagi, 1965, 1977, 1991). Significantly, for Nagi, impairments can range along a number of dimensions[5] that, in turn, can affect "the nature and degree of disability observed" (Nagi 1977, 1991, cited in Altman, 2001, p. 104).

(3) **df. 'functional limitations' =** "Third are *functional limitations* which impairments set on the individual's ability to perform the tasks and obligations of his usual roles and normal daily activities"[6] (Nagi, 1965, p. 102). Nagi identifies five types of "roles" that are relevant to this definition: (1) family roles; (2) work roles; (3) community roles; (4) interactional roles; and (5) self care roles. Given this emphasis, the Nagi model can be taken to have a "role orientation" (Altman, 2001, p. 106). Importantly, there is no necessary connection, for Nagi, between impairment and functional limitation: "not every impairment results in a functional limitation, and functional limitations may result for reasons other than impairments" (Altman, 2001, p.

---

[4] Note that on this account, impairment is a necessary but not sufficient condition for disease. In his (1991), Nagi makes the same point, but uses the term "pathology" instead of "disease": "...although every pathology involves an impairment, not every impairment involves a pathology" (Nagi, 1991, p. 314). Thus, on Nagi's usage, "disease" and "pathology" appear to be roughly synonymous. The IOM adopts Nagi's terminology and usage in its 1991 report; see IOM, 1991, p. 80.

[5] Among these dimensions are the "degree of visibility and disfigurement, stigma, the predictability of the underlying pathology, the prognosis and prospects for recovery or stabilization, threat to life, types and severity of limitations in function they impose and the point of onset in the life cycle" (Nagi, 1991, p. 314, cited in Altman, 2001, p. 104).

[6] As Nagi goes on to explain, there is a dynamic relationship between impairments and social roles, such that depending on the social roles in which one is typically engaged, certain impairments are more likely than others to result in significant functional limitations. Thus, to cite Nagi's example, a master pianist is likely to experience a much greater degree of functional limitation as the result of the loss of a finger than would a truck driver or a teacher, for whom the possession of all five digits on each hand is less critical to the performance of their respective social roles (Nagi, 1965, p. 102). Christopher Boorse uses this illustration as well in his (2009).

106). As an example of the latter type of situation, Altman points to "technological unemployment, which is caused by changes that occur in the work role requirements and are associated with lack of training or changes in expectations rather than lack of ability" (Altman, 2001, p. 106).[7] On Nagi's account, functional limitations fall into at least four primary categories: (1) physical; (2) emotional; (3) intellectual; and (4) sensory. For Nagi, although there is no necessary connection between impairments, functional limitations, and disabilities, functional limitations are "the most direct way impairments contribute to disability" (Altman, 2001, p. 106). Given that both impairments and functional limitations "involve function," the central difference between them is the "level at which the limitations are manifested" (Nagi, 1991, p. 314). Whereas impairments manifest themselves at the "organ" or "system" levels, functional limitations are manifested at the level of the "organism as a whole" (Nagi, 1991, p. 314).[8]

(4) **df. 'sickness' & 'illness' =** "Fourth are forms of behavior that evolve when the presence of disease or pathology is perceived. These behavioral patterns are largely shaped by three general types of influence: (a) characteristics of the pathological condition, that is, type of condition, nature of onset—whether traumatic and unexpected or degenerative with early warnings in signs and symptoms, severity of the associated impairment, and potential for recovery and control; (b) definition of the situation by the afflicted and their reactions, which are greatly influenced by (c), the definition of the situation by others and especially the reactions and expectations of significant others. A number of arguments have been advanced for a seemingly valid distinction between patterns of behavior characteristic of situations of acute short-term conditions and those characteristic of chronic long-term or continued conditions. These two patterns will be referred to as *sickness* and *illness,* respectively" (Nagi, 1965, pp. 102-103).

---

[7] Cf. the discussions, elsewhere in this work, of the MS-Windows controversy, as well as the impact of such technological developments as the telephone on the functional abilities, and resultant limitations, of persons with certain impairments (e.g. deafness).

[8] As Nagi goes on to explain, the relationship between limitations at various levels (organ, system, organism, etc.) is an intransitive one—that is, "[a]lthough limitations at a lower level of organization may not be reflected at higher levels, the reverse is not true" (Nagi, 1991, p. 314). Thus, while "[o]ne could speak of limitations in function at the levels of molecules, cells, tissues, organs, regions, systems, or the organism as a whole," it is nevertheless "important to note that limitations in function at higher levels of organization may result from different impairments and limitations in function at the lower levels" (Nagi, 1991, p. 314).

(5) **df. 'disability' =** "Fifth is what will be labeled *disability*—a pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations.... Disability can be... distinguished from incapacitating sickness on the basis of duration. By definition, the latter is short-term, while the former is of long or continued duration. However, disability and illness overlap when pathology and the corresponding impairment underlying illness are of sufficient severity to limit the individual's functional abilities. The patterns of disability behavior are also subject to three types of influence: (a) characteristics of impairments, degree of limitations imposed, and the potential for rehabilitation; (b) the individual's definition of the situation and his reactions, which sometimes compound the limitations and which are also largely influenced by (c), the definition of the situation by others, their reactions and expectations—especially the reactions of those who are significant in the lives of the afflicted" (Nagi, 1965, p. 103). Thus, "[d]isability conceptualized in terms of behavior is not a stagnant, singular action but a dynamic process that evolves in the context of role interactions" (Altman, 2001, p. 108). Understood in this way, disability "refers to social rather than to organismic functioning. It is an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment" (Nagi, 1991, p. 315).[9] Ultimately, as originally defined and as refined in subsequent publications, Nagi's mature conceptualization of "disability" can be summed up as "the behavior developed within the physical and social context interaction by the individual, based on personality and functional limitation, ...associated with role opportunities" (Altman, 2001, p. 108).

c. Types of predication in the conceptual components

For purposes of identifying the ways in which Nagi characterizes each of the key conceptual components in his model—that is, with a view toward discerning whether they are

[9] Nagi's emphasis on functioning within the context of role interactions—and, in particular, the fact that (on his usage) "the term disability implies a change from prior higher levels of functioning"—might initially seem to rule out being able to count congenital conditions, as well as those acquired during early childhood, as "disabilities" (because in such cases, the respective "higher levels of functioning" might never have been achieved in the first place). In Nagi's conceptual scheme, however, "the concept of disability is used in a generic sense to include those arising from congenital and early childhood conditions as well as those occurring later in life. The comparative reference for the former is the level of functioning of cohorts rather than of prior levels once maintained" (Nagi, 1991, p. 316). Christopher Boorse's (1997) "biostatistical" (BST) approach to disease, discussed elsewhere in this work, also features prominently a comparative reference to the level of functioning of an organism's "cohort."

characterized as predications of intrinsic constitutive properties or as predications of judgment—it will be helpful to begin by recalling the specific definition that Nagi offers for three of his key terms—namely, 'active pathology,' 'impairments," and 'functional limitations.' For Nagi, as we noted above, "active pathology" is "a state of mobilization of the body's defenses and coping mechanisms" (Nagi, 1965, p. 101). "Impairments" are understood as "abnormalities and losses" in anatomy and/or physiology (Nagi, 1965, pp. 101-102). And "functional limitations" are characterized as limitations on ability to perform tasks and obligations in (social) roles and "activities of daily living" (ADLs). We should note, first of all, that "active pathology" refers specifically to the *body's* "defenses and coping mechanisms." Similarly, the definition of "impairments" refers to "abnormalities and losses" in *anatomy* and/or *physiology*. Likewise, the definition of "functional limitations," while containing a reference to "usual roles and normal daily activities," nevertheless places emphasis on the *individual's* inability to perform such tasks and/or roles. The principal difference between impairments and functional limitations, on Nagi's view, is that "[w]hereas impairments manifest themselves at the 'organ' or 'system' levels, functional limitations are manifested at the level of the organism as a whole" (Nagi, 1991, p. 314); nevertheless, even here, the primary focus is on the *individual.* Thus, in the case of all three of these terms, identifying their referents does not require moving "beyond" the individual to a consideration of the broader (physical-social environment).

In a 1991 essay in which he clarifies certain aspects of his theoretical framework, Nagi introduces a distinction between "concepts of properties and attributes," on the one hand, and "relational concepts" on the other. As Nagi explains the distinction, "[c]oncepts of attributes and properties refer to the individual characteristics of an object or a person, such as height, weight, or intelligence. Indicators of these concepts can all be found within the characteristics of the individual" (Nagi, 1991, p. 317). By contrast, "indicators of a relational concept cannot all be accounted for among the attributes of an individual. They include characteristics of other segments of the situation" (Nagi, 1991, p. 317). On Nagi's view, 'pathology,' 'impairment,' and 'functional limitation' are all best understood as being concepts of properties and attributes: "[o]ne need not go beyond examining a person to identify the presence and extent of physiological and

anatomical losses or disorder, or to assess limitations in the functioning of the organism" (Nagi, 1991, p. 317). 'Disability,' on the other hand, is inherently a "relational" concept, on Nagi's view: "its indicators include individuals' capacities and limitations, in relation to role and task expectations, and the environmental conditions within which they are to be performed" (Nagi, 1991, p. 317).

Nagi's distinction between concepts of properties and attributes and relational concepts provides a helpful analogue to the distinction we have been drawing in this work—namely, the distinction between predications of intrinsic constitutive properties and predications of judgment. In the case of Nagi's "concepts of properties and attributes," the properties and attributes in question are limited strictly to the individual—they are "the individual characteristics of an object or a person, such as height, weight, or intelligence" (Nagi, 1991, p. 317). Such properties and attributes can be identified solely by way of examination of the person or object under consideration. They are, in this sense, "intrinsic" to the individual. By contrast, "relational concepts" necessarily involve characteristics not only of the object or individual in question, but also additional features of the situation at hand—e.g., the "role and task" expectations, as well as relevant "environmental conditions." There is thus an interactive relationship between features of the individual and features of the surrounding environment (social, physical, etc.)—thereby rendering 'disability' a "relational," or "extrinsic" property. Consequently, we can speak of Nagi's 'pathology,' 'impairment,' and 'functional limitation' as involving what we have referred to in this work as predications of intrinsic constitutive properties, while Nagi's 'disability' can plausibly be understood as involving a predication of judgment.

2. *International Classification of Impairments, Disabilities, and Handicaps* [ICIDH] (WHO, 1980)

a. Background/Overview

Released for "field trial purposes only" in 1980, the ICIDH focuses on classifying "the outcomes of disease and impairment" (Altman, 2001, p. 109), with a view toward meeting "the great need of rehabilitative personnel for intellectual tools in identifying and communicating about the various consequences of diseases" (Nordenfelt, 1997, p. 618).

The focus of the ICIDH is thus on what are termed the "consequences of disease" (WHO, 1980, p. 23)—that is, impairment, disability, and handicap, all of which are (or can be) the result of some underlying disease. 'Disease' is cashed out in terms of what the authors refer to as a "medical model of disease,"[10] according to which disease is a "manifested pathology," from which certain consequences—impairment, disability, handicap—are understood to follow: disease causes (or ensues in) impairments, which can then cause disability, which can then cause handicap. Schematically, this can be represented as follows: Disease→Impairment→Disability→Handicap. In a nutshell, the basic idea is that the entire sequence begins with a manifested pathology (i.e., a pathological condition of which one is aware, even if that condition has not yet been diagnosed), from which impairment, disability, and/or handicap may—or may not—ensue. Importantly, the causal links are not envisioned as being necessary: impairment may, but need not, result in disability; disability, in turn, may but need not result in handicap, depending on whether or not appropriate intervention is undertaken at each stage. Moreover, interventions at one stage can affect the others, such that an individual can move back and forth along the impairment-disability-handicap continuum. In these ways, the schema is designed to facilitate social and other responses at all stages of the impairment-disability-handicap process, by identifying relevant points at which intervention might occur (WHO, 1981, pp. 10-11).

The ICIDH explicitly introduces a distinction between "disturbances at the organ level"—i.e., impairments—and "disturbances at the level of the person," i.e. disabilities. Impairments are understood as "abnormalities" in body structure and appearance, or in organ system or function. Disabilities, by contrast, refer to the effects that impairments may have on the individual in terms of her performance and/or activity—hence, they are "person-level" disturbances. Finally, "handicaps" are understood as "disadvantages experienced by the individual" as a result of either impairments or disabilities. Here, impairments and/or disabilities interfere with the individual's ability to perform key "social roles," understood in terms of social norms related to such areas as "orientation," "physical independence," "mobility," "occupation," "social integration," and

[10] The framers of the ICIDH represent this "medical model of disease" schematically as follows: etiology→pathology→manifestation (WHO, 1980, p. 10).

"economic self-sufficiency" (WHO, 1980, p. 14). Handicaps thus "reflect interaction with and adaption to the individual's surroundings" (WHO, 1980, p. 14).

b. Conceptual components

The key conceptual components of the ICIDH are (1) disease and disorders, (2) impairment, (3) disability, and (4) handicap, respectively.

(1) Disease and disorders

The ICIDH model uses "disease and disorders" as its starting point. The operative notion here is that a pathological condition has been "exteriorized"—that is, it has been manifested or made evident to the individual or to those around her. "This 'exteriorized' (but not necessarily diagnosed[11]) pathology or awareness of illness," Altman explains, "leads to the recognition of the impairment or abnormalities of body structure or appearance that serve as the basis for most models of disability" (Altman, 2001, pp. 103-104).

(2) Impairment

In ICIDH, impairment is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1980, p. 27).[12] Here, the term is interpreted to be broader than "disorder," and also is taken to subsume "functional limitation" within its ambit (Altman, 2001, p. 105; cf. WHO, 1980, p. 27). Impairments are understood as a deviation from "some norm in the individual's biomedical status," as determined by "those qualified to judge physical and mental functioning according to generally accepted standards" (WHO, 1980, p. 27).

Impairments, on the ICIDH account, are described as "threshold phenomena"—that is, they are either present or not present, and are identified on that basis (WHO, 1980, p. 36) In other words, they are "all-or-nothing"—they are not degreed properties or phenomena.

(3) Disability

In the "third component" place for the ICIDH-1, we find "disability" rather than "functional limitation" (as in the Nagi model). On Altman's analysis, what Nagi refers to as "functional

---

[11] A key point of contrast between the ICIDH-1 and the Verbrugge/Jette models, to be discussed in the following section.

[12] Note that this is a population-based concept of "observed normal structure/function" where "normal" refers to falling within two standard deviations of the mean anatomy and physiology.

limitation"—that is, limitation at the system-level rather than the person-level[13]—has largely been subsumed, by the ICIDH-1, under the heading of "impairment." Here, on the ICIDH, the term 'disability' appears to refer primarily to limitation at the *person* (rather than system) level (Altman, 2001, p. 107).

Disability is explicitly defined by the ICIDH as "[a]ny restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p. 29, quoted in Barnes & Mercer, p. 13).[14] It is identified with respect to a "norm" of individual performance (at the person level), and, further, requires an awareness on the part of the affected individual of a "change in identity" (WHO, 1980, p. 28).

Disability, on the ICIDH framework, is a "dynamic" process, one that involves deviation from a normative view of the "the normal." On this account the definition of disability involves an implicit appeal to a "norm"—namely, "activity in the manner or within the range considered appropriate for nonimpaired persons." In this sense, "unimpaired persons" become the reference with respect to which "impaired persons" are evaluated.

The norms implicit in 'impairment' and 'disability' (and, as we will see, in 'handicap" as well) can be derived from one of three sources. First, some norms are grounded in statistical concepts of "normality"; this is particularly common when quantitative phenomena (e.g., body height) are being categorized. Second, norms may be derived from an ideal of some sort (understood either as a "threshold phenomenon," or else in terms of specific inclusion/exclusion criteria). Finally, some norms are "determined by social responses"; here, the central idea is that "an individual's perceptions – his belief that he has a problem – or the identity that other people attribute to the individual can both give rise to disadvantage" (WHO, 1981, pp. 33-34).

In contrast with impairments, "disabilities" are *not* "threshold phenomena"; instead, they are properly understood as "failures in accomplishment." Therefore, "gradations" of disability are

---

[13] As we will see, most of the models under consideration here feature some sort of distinction between "levels." Potentially, any number of different levels could be specified, depending on one's purposes. One might, for example, distinguish among phenomena that occur at the "cellular," "tissue," "organ," "system," "person"/"organism as a whole," or "social" levels. As we saw earlier, Nagi distinguishes between "impairments," which occur at the organ or system levels, and "functional limitations," which are manifested at the level of the "organism as a whole" (Nagi appears to use "organism as a whole" synonymously with "person") [Nagi, 1991, p. 314]. Most of the models under consideration here feature at least a "system-versus-person-level" distinction.

[14] Note that this is also a population-based concept of observed normal function.

possible (i.e., one can be more or less "disabled" with respect to a given activity) (WHO, 1980, pp. 37-38).

(4) Handicap

In the ICIDH, the World Health Organization defined "handicap"—the model's fourth component—as follows:

> In the context of health experiences, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO, 1980, p. 14, quoted in Altman, 2001, p. 109).[15]

Given its focus on classification—specifically, classifying "the outcomes of disease and impairment" (Altman, 2001, p. 109)—the ICIDH moves away from Nagi's focus on the interactive nature of disability toward an emphasis on the *disadvantage* experienced by persons with impairments and/or disabilities in various social contexts.[16] Here, disadvantage is seen as a "discordance between an individual's performance and the expectations of the group, imposed by the group and arising despite the individual's intentions" (Altman, 2001, p. 109). This discordance is understood as a "departure from a group norm"; the norm itself, as we saw above, could be of a number of different varieties: a statistical measure; an idealization; an arbitrary criterion; or, perhaps, based on (or derived from) social reactions indicating the perception of a "problem" (Altman, 2001, p. 109). Importantly, the framers of the ICIDH limited the scope of "disadvantage" to "disadvantages associated with activities that are related to existence and survival," specifically the "basic needs" for (1) orientation; (2) independence; (3) mobility; (4) occupation; (5) social integration; and (6) economic sufficiency (Altman, 2001, p. 109, citing WHO, 1980, p. 39).[17] As its

---

[15] Note that this is a *role-based* concept.

[16] The ICIDH stresses that the notion of *disadvantage,* central as it is to the framework's definition of 'handicap,' is not synonymous with "dependence." Indeed, human beings are most accurately described as being *interdependent*—needing one another to meet a variety of needs, including social needs, the satisfaction of which can, in many cases, mitigate the disadvantages associated with "irremediable physiological and safety needs" (WHO, 1981, p. 40). For a recent philosophical discussion of the significance of "interdependence," see Alasdair Macintyre's (1999) *Rational Dependent Animals.*

[17] In this regard,

> [t]he modelers recognized that survival roles do not exhaust the dimensions of handicap but found that higher needs are more difficult to measure and categorize in any mutually exclusive and hierarchical way. Since survival is the most important in a hierarchical scheme, they chose to limit the third classification to the basic need for orientation, independence, mobility, occupation, social integration, and economic sufficiency (Altman, 2001, p. 109).

authors acknowledge, of course, this understanding of 'handicap' rests on a key value assumption—namely, that "existence and survival are necessary and good" (WHO, 1980, pp. 38-39).

(5) The relationship between impairment, disability, and handicap

The authors of the ICIDH stress that there is no *necessary* relationship between disability, on the one hand, and disadvantage (handicap) on the other. To illustrate: on this account, the paralysis (and inability to walk) that results from polio would be an "impairment." The associated "disability" would be the inability to ambulate without assistance (mechanical or otherwise). But neither this impairment nor that disability would necessarily result in "handicap." Only if, for example, employers refused to hire the person who suffers from the disability (where the refusal to hire was *based on* the fact of having the disability), would it then become a "handicap." Thus, "[a] disability becomes a handicap due to the choices of individuals and organizations. Handicaps are the result of social choices; they are not part of the 'fabric of the universe'" (Steinbock, 2000, p. 114).

Several analytic observations are worth making here. On this account one need not actually *be* 'disabled' in order to be 'handicapped.' This flows from the fact that 'handicapped' is defined as "the social disadvantage that results from an impairment or a disability." This allows for the possibility that one might be *perceived* as being disabled without actually *being* disabled, and that "social disadvantage" might thereby accrue to an individual. In other words, one might be impaired yet not (in fact) be restricted in one's ability to perform a given activity or social role "in the manner or within the range considered appropriate for nonimpaired persons"—yet others might nevertheless *perceive* the individual in question to be so restricted, as a result of which the individual may suffer "social disadvantage" despite being (merely) impaired and not also disabled. In this way, the ICIDH account allows for a direct link between impairment and handicap, in addition to the more common three-way impairment-disability-handicap link.

c. Types of predication in the conceptual components

We have seen in our discussion that, on the ICIDH, disease/disorder, impairment, and disability focus on the *individual,* but handicap brings a *social* dimension into the mix—so it should not surprise us if we find a similar pattern vis-à-vis the types of predications (i.e., intrinsic versus extrinsic) involved in each of these terms as we saw with the Nagi model. Let us see if this is indeed the case.

First, recall that on the ICIDH, impairments are understood as "abnormalities" in body structure and appearance, or in organ system or function. Disabilities, by contrast, refer to the effects that impairments may have on the individual in terms of her performance and/or activity—hence, they are "person-level" disturbances. Finally, "handicaps" are understood as "disadvantages experienced by the individual" as a result of either impairments or disabilities. Here, we see a similar pattern of *intrinsic* property attributions (impairments and disabilities), followed by an "outcome term" that involves an *extrinsic* (relational) property attribution. In the case of impairments, the term refers to *body structures* and/or *appearance,* or *organ systems* and their *functions,* that are "abnormal." Disabilities occur at the "person-level," but involve the "performance" or "activity" *of the individual.* Handicaps, by contrast, refer to the ways in which an individual is *disadvantaged* by those abnormalities in body structure/appearance and/or organ system/function, which inevitably involves comparative notions of relative advantage or disadvantage—thus rendering "handicap" a relational, or *extrinsic* property.

Textual evidence for this interpretation can be gleaned from passages from the ICIDH in which the sense and referents of the various terms are discussed. For example, the definition of 'impairment' given at page 28 of the ICIDH encompasses "any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1980, p. 28, quoted in Altman, 2001, p. 105)—clearly features of the *individual* rather than of her surrounding environment (social, physical, or otherwise). 'Disability,' in turn, is defined with reference to a "norm" of *individual* performance at the person level (WHO, 1980, p. 28)—again supporting the notion that this term is intended to involve an attribution of *intrinsic* constitutive properties. Finally, 'handicap' is conceptualized in "relational" terms, such that an attribution of extrinsic properties is inevitably involved:

> In the context of health experiences, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (*depending on age, sex, and social and cultural factors*) for that individual (WHO, 1980, p. 14, quoted in Altman, 2001, p. 109, italics added)

This understanding of handicap, relying as it does on the notion of "disadvantage" relative to other persons in society, is inherently comparative and, therefore, relational. This "disadvantage" is seen as a "discordance between an individual's performance and the expectations of the group, imposed by the group and arising despite the individual's intentions" (Altman, 2001, p. 109). In short, "handicap" is (on the ICIDH model) something that is "said of" an individual—an *extrinsic,* or *relational* predication—on the basis of the (social) "disadvantage" that is brought upon her in response to her impairment and/or disability (her "intrinsic" features).[18]

This latter point—namely, that the "outcome term" of the ICIDH model, 'handicap,' is conceptualized as involving an inextricable mix of "intrinsic" and "extrinsic" factors—suggests, in turn, the possibility that *any* adequate model of disability must include at least one term (typically the 'outcome term') that involves this sort of combination of "intrinsic" and "extrinsic" predications. Whether or not this possibility is indeed the case, and whether or not it is borne out in the other models under review here, remains to be seen.

3. Verbrugge/Jette model (1994)

The Verbrugge/Jette model is of particular interest because it was developed in the context of and designed explicitly with a view toward the specific needs of the clinical and rehabilitation settings. Verbrugge and Jette developed their model against the background of experienced practical difficulties in implementing the ICIDH. As they explain, even though the ICIDH received broad political support, it nevertheless ran into implementation difficulties during

---

[18] Strictly speaking, as the authors of the ICIDH acknowledge, the "intrinsic" and "extrinsic" features of 'handicap' are not so easily disentangled; in fact, they argue, these features are inextricably intertwined. For example,

> [s]ubnormality of intelligence is an impairment, but it may not lead to appreciable activity restrictions; factors other than the impairment may determine the handicap because the disadvantage may be minimal if the individual lives in a remote rural community, whereas it could be severe in the child of university graduates living in a large city, of whom more might be expected (WHO, 1980, p. 31).

This latter example, the framers of the ICIDH point out, demonstrates well how "handicap" always involves *both* "intrinsic" and "extrinsic" features, such that in practice the attempt to disentangle these features is futile; indeed, as they put it, "any attempt to differentiate between intrinsic and extrinsic components of handicap in fact neglects the fundamental property of this concept, which expresses the resultant of the interaction between the intrinsic and the extrinsic" (WHO, 1980, p. 31).

field trials. In particular, they note that "scientific researchers have had trouble using ICIDH as a basis for hypothesis development and study design, citing problems of conceptual clarity, internal consistency, and measurement feasibility in surveys" (Verbrugge & Jette, 1994, p. 2). Part of the reason for these difficulties, Verbrugge and Jette imply, is that Saad Nagi's theoretical interests were primarily sociological rather than taxonomic, and since the ICIDH was based largely on Nagi's scheme, it inherited whatever shortcomings the Nagi model might have had (Verbrugge & Jette, p. 2). In response to these difficulties, Verbrugge and Jette sought to develop a model that would be both "social" and "medical"—hence, "sociomedical"—so as to accommodate the practical needs of clinicians and rehabilitation professionals, while also retaining the theoretical insights of the Nagi scheme and the taxonomic comprehensiveness of the ICIDH framework.

a. Background/Overview

To that end, Verbrugge and Jette focused their attention on "delineat[ing] the pathway from pathology to various kinds of functional outcomes" (i.e., impairment, functional limitation, disability, etc.). Verbrugge and Jette put their account of that "pathway" in terms that they viewed as more appropriate for medical and survey research, then went on to place particular emphasis on "predisposing and introduced factors that speed up and slow down the pathway"—that is, "exacerbators" and "interventions," respectively. The rationale for this sort of approach is that "in real life, the main pathway [from pathology to disability via impairment and functional limitation] does not occur in a pure untampered way. There are always social, psychological, environmental (etc.) factors operating to alter it" (Verbrugge & Jette, 1994, pp. 2-3). The model is thus an attempt to capture the various biopsychosocial factors involved in the disablement process. In this respect, Verbrugge and Jette saw themselves as joining in and contributing to an ongoing discussion already moving in that general direction, a trend initiated by advocates of both the Nagi and ICIDH schemes (Verbrugge & Jette, 1994, pp. 2-3).

b. Conceptual components

Key terms in the Verbrugge/Jette model include 'disablement,' 'pathology,' 'impairments,' 'functional limitation,' and 'disability.' *Disablement* is defined with reference to "impacts that chronic and acute conditions have on the functioning of specific body systems and on people's

abilities to act in necessary, usual, expected and personally desired ways in their society." For Verbrugge and Jette, "[t]he term 'disablement' is general, covering all consequences of pathology for functioning (Verbrugge & Jette, 1994, p. 3).

Pathology, in turn, refers to "biochemical and physical abnormalities that are detected and medically labeled as disease, injury, or congenital/developmental conditions" (Verbrugge & Jette, 1994, p. 3). "Abnormalities" are identified on the basis of threshold criteria for clinical significance; once a given abnormality crosses the relevant threshold, it is considered a "diagnosed condition," that is, a *pathology* (Verbrugge/Jette, 1994, p. 3).[19]

Impairments are "dysfunctions and significant structural abnormalities in specific body systems" (Verbrugge & Jette, 1994, p. 3). By "significant" the authors mean that the abnormality is such that it "can have consequences for physical, mental, or social functioning" (Verbrugge & Jette, 1994, p. 3). These consequences can be localized in the specific area of the pathology, but can also occur in secondary locations as well; moreover, the consequences can occur either immediately or on a delayed basis. Thus, for example, a hip injury might directly impair hip function; however, an individual with a hip injury who continues to walk on that hip can eventually experience impaired functioning of her back muscles (Altman, 2001, pp. 104-105).[20]

Functional limitations, on the Verbrugge/Jette model, refer to "restrictions in performing fundamental physical and mental actions used in daily life by one's age-sex group"; the "fundamental" actions in question are those actions which "constitute the basic interface" between the individual and the social-physical context in which she acts in her daily life (Verbrugge & Jette, 1993, p. 3). For Verbrugge and Jette, functional limitations are understood "in terms of the

---

[19] The requirement of explicit *diagnosis* represents a recognition that:

> many of the bodily changes represented by pathology are not always directly measurable in medical practice where detection relies on evaluation of manifest signs and symptoms. Their perspective requires a diagnosis since it represents a pathology that has satisfied clinical significance and can therefore be considered public (Altman, 2001, p. 102).

As a consequence, undiagnosed pathological conditions would be ruled out on this construal of "pathology/disease."

[20] The Verbrugge/Jette model's requirement of explicit *diagnosis* for the "pathology/disease" component (see previous note) has a methodological parallel when it comes to the "impairment" component. Here,

> [i]mpairments are identified via medical procedures, including exams, laboratory tests, imaging, and the patient's medical histories and reports of symptoms. This latter method is an extension of their original concept of the necessity of a diagnosis as a precondition for pathology (Altman, 2001, pp. 104-105)

Interestingly, this methodological requirement also has a further epistemological consequence: "[a]s in the first WHO model, this emphasis on diagnosis or 'exteriorization' implies a need for legitimation from the medical profession," which is a "central element" of administrative definitions of disability (Altman, 2001, pp. 104-105). This, in turn, has certain practical implications: "From this perspective, self-reports are questionable and effects from new conditions, such as chronic fatigue syndrome, fibromyalgia, or Gulf War syndrome, are invalid until such conditions are identified and accepted by the medical system" (Altman, 2001, pp. 104-105).

physical and mental actions that are required for an individual to interact with their social and physical environment, including overall mobility; discrete motions and strengths; trouble seeing, hearing, or communicating; and more general examples" (Altman, 2001, p. 106). Where Nagi's focus was on the effects of functional limitations on the *roles* played by individuals, the Verbrugge/Jette model focuses its attention on *tasks* performed by individuals (Altman, 2001, p. 106).

Finally, *disability*—the "outcome term" (Altman, 2001) of the Verbrugge/Jette model—is defined as "experienced difficulty doing activities in any domain of life (the domains typical for one's age-sex group) due to a health or physical problem" (Verbrugge & Jette, 1994, p. 4). "Activity" is understood comprehensively, to include "all domains of human activity from self-care to leisure activities" (Altman, 2001, pp. 109-110), "from hygiene to hobbies, from errands to sleep" (Verbrugge & Jette, 1994, pp. 4-5). On this model, disability is not a property or feature that is "inherent in a person." Instead, "it denotes a relationship between a person and his/her environment.... Disability occurs for a given activity when there is a gap between personal capability and the activity's demand" (Verbrugge & Jette, 1994, p. 9).

Functional limitations and *disability* can be distinguished in terms of their respective foci: where the former focuses on "actions" or "tasks" in which the individual engages, the latter focuses on the "activities" or "roles" played by the individual in her normal social environment. The former is taken to be a "generic," "situation-free" notion, whereas the latter, as social, is inherently "situational" (Verbrugge & Jette, 1994, p. 5).

c. Types of predication in the conceptual components

In the Verbrugge/Jette (1994) model, *pathology* refers to "biochemical and physical abnormalities that are detected and medically labeled as disease, injury, or congenital/developmental conditions" (Verbrugge & Jette, 1994, p. 3). The focus on "biochemical and physical abnormalities" lends credence to an interpretation of this term as involving a predication of intrinsic constitutive properties (an *intrinsic* property). '*Impairments*,' in turn, are "dysfunctions and significant structural abnormalities in specific body systems" (Verbrugge & Jette, 1994, p. 3). Here again, the reference to "specific body systems" would seem to lead us

toward interpreting this as involving an *intrinsic* predication. *Functional limitations,* on the Verbrugge/Jette model, refer to "restrictions in performing fundamental physical and mental actions used in daily life by one's age-sex group"; the focus on "fundamental physical and mental actions" seems once again to involve the predication of intrinsic constitutive rather than "relational" properties. Finally, however, *disability* is defined as "experienced difficulty doing activities in any domain of life (the domains typical for one's age-sex group) due to a health or physical problem" (Verbrugge & Jette, 1994, p. 4). Here, the references to life "domains," as well as to the "age-sex group" in terms of which the domains are identified, supports an understanding of this term as involving a "relational," or extrinsic, predication—that is, a predication of judgment rather than a predication of intrinsic constitutive properties.[21]

Further reasons for drawing these conclusions include the fact that, on the Verbrugge/Jette account, *functional limitations* are construed in such a way that tests of relevant physical and mental activities measure the individual's ability to do those tasks "on her own"—that is, "without someone's assistance," and/or "without equipment assistance" (1994, pp. 3-4)—thereby suggesting that the framers of the model intended that term to refer to *intrinsic* constitutive properties of the individual rather than *extrinsic* relational properties involving the interaction between the individual and her environment. Moreover, as we noted previously, for Verbrugge and Jette, *functional limitations* and *disability* can be distinguished in terms of their respective foci: where the former focuses on "actions" or "tasks" in which the individual engages, the latter focuses on the "activities" or "roles" played by the individual in her normal social environment. Arguably we see yet again an "individual in isolation" versus "individual in interaction with society/environment" distinction, thereby lending further support to our interpretation of the types of predication involved in each of these terms.

C. Institute of Medicine models: IOM-1 (1991) and IOM-2 (1997)

[21] It might be objected here that since the definitions of *both* functional limitation *and* disability include a reference to the individual's "age-sex group," both terms are more properly thought of as being "relational" in the sense in which we are using that term here—that is, as involving a predication of judgment rather than a predication of an intrinsic constitutive property. However, the material in the next paragraph may give us some reason for preferring the analysis presented here, where 'functional limitation' is intrinsic and 'disability' is extrinsic. Alternatively, it may be possible to soften our claims here, to the effect that the respective terms are interpreted as being *primarily* intrinsic or extrinsic, though ultimately involving a combination of the two (i.e., intrinsic and extrinsic). In any event, the relevant point for present purposes is simply that *at least one* of the key conceptual terms in this model involves an *intrinsic* predication, while *at least one* of the terms involves *extrinsic* predication.

1. IOM-1 (1991)

a. Background/Overview

In 1991, the Institute of Medicine convened a Committee that was given the express mandate of developing "a national agenda for the prevention of disabilities" (Tarlov, 1991, p. vi). As its name suggests, the Committee's report—entitled *Disability in America: Toward a National Agenda for Prevention*—focuses its attention primarily on "preventing a potentially disabling condition from developing into disability and on minimizing the effects of such conditions on a person's productivity and quality of life" (Tarlov, 1991, p. v). The expressed focus on prevention of potentially disabling conditions becoming full-blown cases of disability underscores, in turn, the need for conceptual clarity about disability and related concepts. The IOM thus seeks in this report to develop a model of disability that will be helpful for studying the progression from potentially disabling condition to disability, as well as to "facilitate the development of improved surveillance systems, an epidemiology of disability, and more effective means of prevention" (IOM, 1991, pp. 3-4).

To this end, the IOM developed a model of disability based on the Nagi (1965) and World Health Organization (1980) models, then added to those models additional elements—specifically, emphases on "risk factors" and "quality of life" (IOM, 1991, p. 4). In building on the work of the ICIDH in particular, the committee took note of the fact that numerous "inconsistencies" had been found in various parts of that classification scheme, particularly areas of overlap between the categories of "disability" and "handicap." They thus saw a need for greater clarity in concepts related to disability. Moreover, they also took note of the fact that, increasingly, the term 'handicap' had been coming under attack, particularly from disability rights quarters, as being demeaning and reinforcing stereotypes about persons with disabilities.[22] For these reasons, the IOM eschewed the use of the term 'handicap,' electing instead to develop a model that, in

---

[22] As the authors explain it,
[t]raditionally, *handicap* has meant limitations in performance, placing an individual at a disadvantage. Handicap sometimes has been used to imply an absolute limitation that does not require for its actualization any interaction with external social circumstances. In recent years, the term has fallen into disuse in the United States, primarily because people with disabling conditions consider handicap to be a negative term. Yet the shadow of 'handicap' as a commonly used term hovers behind the concept of quality of life, and has the effect of reducing quality of life, even though impairment, functional limitation, and disability do not necessarily do so. Much as the term 'cripple' has gone out of style, handicap seems to be approaching obsolescence, at least within the community of people with disabilities in the United States (IOM, 1991, p. 6).

their view, both avoided the inconsistencies and unclarities inherent in the ICIDH classification scheme and, simultaneously, avoided the ICIDH's "consequences of disease" emphasis, along with any need for use of the contested term 'handicap.'[23] Taking note of the process that had already begun toward revising the ICIDH—a process that ultimately resulted in publication of the *ICF*, in 2001—the IOM committee expressed its hope that their proposed framework would be "considered as a viable alternative in the revisions of the WHO ICIDH" (IOM, 1991, p. 6).

b. Conceptual Components

As with the Nagi and ICIDH frameworks, the 1991 IOM model also features four key conceptual components, or "stages" (of the "disabling process")—namely, *pathology, impairment, functional limitation*, and *disability*. Importantly, however, the IOM model places greater emphasis on the "interactive" and contingent nature of the relationships between these distinct stages. Thus, "[i]n the course of a chronic disorder, one stage can progress to the next. But depending on the circumstances, progressively greater loss of function need not occur, and the progression can be halted or reversed" (IOM, 1991, p. 6). Further, as mentioned previously, the IOM model also explicitly introduces elements related to "risk factors" and "quality of life," emphasizing once again the interactive and dynamic relationships between and among these elements.

The core of the IOM-1 model is what is referred to as the *disabling process.* Generally speaking, this involves a progression from pathology to impairment, from impairment to functional limitation, and from functional limitation to disability. However,

---

[23] For similar reasons, the IOM committee also chose to use the phrase "people with disabilities" as opposed to "disabled people." In explaining their rationale for this move, they note that

> [i]n common parlance, *disability* is a value-laden, stereotyping term that categorizes people according to their impairments. People who have reduced ability to perform expected activities—that is, those who are said to have 'disabilities'—are often viewed as permanently sick. Such a perception deprives many people with disabilities of the opportunities that should accompany their membership in society. The disability-rights and independent-living movements have struggled to overcome this stereotyping (IOM, 1991, p. 36).

As a result, the IOM committee concurs with the argument against the use of the phrase "disabled people," and elects instead to use "people with disabilities." They "hasten to point out," moreover, that "a person's identity is the product of a host of characteristics and that disabling conditions are but a few of them" (IOM, 1991, p. 36). According to the committee, this linguistic move—though seemingly minor—actually has great import, for it underscores the fact that "external factors, like stereotypes, impose obstacles to the performance of chosen roles. In fact, it is external factors like these that can transform a functional limitation into a disability" (IOM, 1991, p. 36).

The significant upshot of the foregoing is that rather than being pictured as a "static endpoint," disability is instead described as a "component of a process" (Tarlov, 1991, p. v-vi). As such, the authors of the IOM report present disability as "a social issue and not just a physical condition" (Tarlov, 1991, p. vi). In this context, they view their approach as going "beyond the traditional medical model to consider and address the needs of people with disabling conditions after those conditions exist and after they have been 'treated' and 'rehabilitated'" (Tarlov, 1991, p. v-vi). Importantly, they also caution that "...although it is important to learn how to prevent and ameliorate physical and mental conditions that can cause disability, it is equally important to recognize that a disabling condition is only a single characteristic of the person who has it" (Tarlov, 1991, p. viii).

> [a]lthough it seems to indicate a unidirectional progression from pathology to impairment to functional limitation to disability, and although a stepwise progression often occurs, progression from one state to another is not always the case. An individual with a disabling condition might skip over components of the model, for example, when the public's attitude toward a disfiguring impairment causes no functional limitation but imposes a disability by affecting social interaction (IOM, 1991, p. 8, 10).

Thus, "[a] variety of personal, societal, and environmental factors can influence the progression of a disabling condition from pathology to disability" and these factors can, in turn, also affect "the degree of limitation or disability a person experiences and the occurrence of secondary conditions" (IOM, 1991, p. 10).[24] Ultimately, then, the IOM-1 model is a thoroughly interactive model of disability: "disability is the product of a complex interactive process involving biological, behavioral, and environmental (social and physical) risk factors, and quality of life" (IOM, 1991, p. 10.)

c. Types of predication in the conceptual components

The IOM-1 (1991) model explicitly defines the terms 'pathology,' impairment,' and 'disability' as follows:

> The term *disability* as used in this report refers to limitations in physical or mental function, caused by one or more or health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do.... The term *health condition* includes *pathology,* or active disease, as well as *impairment,* which refers to losses of mental, anatomical, or physiological structure or function owing to injury, active disease, or residual losses from formerly active disease. The term *disabling*

---

[24] Moreover, as noted above, "quality of life is an integral part of the disabling process," and "each successive stage in the disabling process poses an increasing threat of diminished quality of life" (IOM, 1991, p. 10). A further, important aspect of the "disabling process" as described in the IOM-1 model is that multiple conditions can result in multiple disabilities; indeed, initial conditions and disabilities can spawn secondary conditions and disabilities, and so forth, with varying degrees of interaction among the various conditions and disabilities. As the IOM committee explains the point,

> [i]n considering the disabling process, it is important to recognize that persons can have multiple chronic conditions, multiple functional problems, and even multiple disabilities because each role that an individual normally performs produces an opportunity for disability to manifest. Thus an independent disabling condition can develop in a person who already has one. A more likely situation, however, is one in which additional disabling conditions result as a consequence of a primary disabling condition (IOM, 1991, p. 94).

condition refers to any physical or mental health condition that can cause disability (p. 35).

Note that the term 'disability' refers to "limitations in physical or mental function" *in relation to* the carrying out of "socially defined tasks and roles that individuals generally are expected to be able to do"—clearly a *relational* picture—whereas the terms 'pathology' and 'impairment' refer to "active disease" and "losses of mental, anatomical, or physiological structure or function owing to injury, active disease, or residual losses from formerly active diseases," without any reference to features external to the individual. Consequently, it seems reasonable to conclude that, on the IOM-1 model, 'pathology' and 'impairment' are conceptualized as involving *intrinsic* predications, whereas 'disability' is conceived as involving *extrinsic* predications.

Consider some further textual evidence in support of this interpretation of the IOM-1 model as following the (by now familiar) *intrinsic-intrinsic-intrinsic-extrinsic* pattern of predications vis-à-vis the key terms 'pathology,' 'impairment,' 'functional limitation,' and 'disability,' respectively. First, in the IOM-1 model, "*[p]athology* refers to cellular and tissue changes caused by disease, infection, trauma, congenital conditions, or other agents" (IOM, 1991, p. 79).[25] Here, the term 'pathology' refers to changes at the cellular and tissue levels—clearly features *intrinsic* to the individual. Second, *impairment* is defined as "a discrete loss or abnormality of mental, physiological, or biochemical function," including "losses caused by all forms of pathology" (IOM, 1991, p. 80).[26] The "impairment" concept encompasses "anomalies, defects, or losses" and is located at the organ or organ system level rather than the level of the organism as a whole—that is to say, "impaired" is properly said of an *organ/organ system*, but not of an *organism,* taken as a whole (IOM, 1991, p. 80). Here again, the reference is to features that are *intrinsic* to the individual—namely, mental, physiological, and biochemical function. Third, the IOM-1 framework explicitly adopts Nagi's conceptualization of *functional limitation* as "effects manifested in the

[25] Pathology can be brought about by "predisposing" risk factors, which can be "biological, lifestyle and behavioral, or environmental (physical or social)" (IOM, 1991, p. 80).

[26] Importantly, while the same impairment might be associated with different "etiologies" and "different types of pathology," on the one hand, "all pathologies," on the other hand, "...are accompanied by impairments" (IOM, 1991, p. 80).

performance or performance capacity of the person as a whole" (IOM, 1991, p. 80).[27] Thus, although broader in scope than "pathology" or "impairment," "functional limitation" still involves reference to the *individual*, and her *intrinsic* features, rather than to extrinsic or relational features. Finally, *disability* is defined in the IOM-1 as "the expression of a physical or mental limitation in a social context"—that is, "the gap between a person's capabilities and the demands of the environment" (IOM, 1991, p. 81). By contrast with the notions of pathology, impairment, and functional limitation—all of which "involve different levels of organismic function"—disability has reference to "social rather than organismic function" (IOM, 1991, p. 81). Consequently, factors external to the individual play a unique role in disability, one which they do not play in pathology, impairment, and functional limitation: "[d]isability is defined by the attributes and interaction of the individual and the environment, whereas the preceding stages are defined solely by characteristics of the individual" (IOM, 1991, p. 82). Disability can thus be understood as a "relational attribute," with the relevant relata being features of the individual, on the one hand, and features of the environment on the other (IOM, 1991, p. 82). More specifically, the "features" in question are the functional limitation(s) of the individual and the environmental conditions and "demands" imposed upon the individual. Thus, whereas it is possible to identify pathology, impairment, and functional limitations by way of "examination and testing of the individual," disability, as a "relational attribute," can only be identified in terms of "the interaction of an individual's functional limitation with the demands of expected tasks and roles and with the environmental conditions under which roles and tasks are to be performed" (IOM, 1991, p. 82). The "interactive" nature of disability suggests that there might be more than one way of addressing disability—namely, either by changing the individual's functional capacities, on the one hand, *or* by changing the demands imposed on the individual by her surrounding environment. This "interactive" account of the nature of disability suggests, in turn, that the framers of the IOM-1 model intended that 'disability' be understood as involving a predication of extrinsic, or relational properties, rather than intrinsic constitutive properties, as with 'pathology', 'impairment', and 'functional limitation'.

---

[27] Consistent with Nagi's usage, "[a]ll functional limitations result from impairments, but not all impairments lead to functional limitation..." (IOM, 1991, p. 80).

2. IOM-2 (1997)

a. Background/Overview

Noting the sizeable gap between the numbers of individuals with disabilities in America (as of 1997, approximately 49 million, or one of every seven citizens) and the annual disability-related costs to the nation (approximately $300 billion), on the one hand, and the amount of resources (approximately $153 billion) devoted to research on rehabilitation science and engineering, on the other, the United States Congress requested that the Institute of Medicine prepare a report focusing on the relationship between disability and rehabilitation science and engineering, with a set of recommendations for enhancing the latter in an effort to prevent and/or ameliorate the effects of the former. To that end, the IOM convened a Committee on Assessing Rehabilitation Science and Engineering, which produced a report in 1997 entitled *Enabling America: Assessing the Role of Rehabilitation Science and Engineering.*

b. Conceptual Components

Key conceptual terms such as 'pathology,' 'impairment,' 'functional limitation,' and 'disability' are defined more or less identically in this report as in the 1991 IOM report, and so will not be rehearsed here. Most importantly, the IOM 1997 report carries over from the 1991 report the central idea that "disability is not inherent in the individual, but rather is a product of the interaction of the individual with the environment" (IOM, 1997, p. 8), and the emphasis here is on clarifying and developing the conceptual account of that dynamic, person-environment interaction.[28]

---

[28] To that end, the report begins with the 1991 IOM model as its starting point, then adds modifications to that model intended both to improve it, and to render it more useful for rehabilitation contexts. The need for improvement of the 1991 model was occasioned by recognition of several problems, or "shortcomings," which use of that earlier model had made clear in the intervening years. We shall attend to two of those shortcomings here. First, the 1991 model appeared to imply that "the disabling process is unidirectional, progressing inexorably toward disability without the possibility of reversal" (IOM, 1997, p. 67). This implication was suggested, in particular, by the use of arrows in the visual depiction of the 1991 model, which pointed in one direction only—namely, to the right, *toward* "disability." In an effort to rectify this shortcoming, the new model adds left-pointing arrows as well, indicating that individuals can move in both directions along the "enabling-disabling process," either toward or away from disability. "Risk factors" and "enabling factors" alike are now grouped in a single category—labeled "transitional factors"—in order to show that these various factors play a key role in determining whether an individual moves (or transitions) from one stage to another, in either direction, in the disabling-enabling process. In addition, a "no disabling conditions" designation is added to the model, in order to make it clear that the rehabilitative process can in fact be successful—that is, "there is a beginning and an end to the disabling process when a pathology, impairment, functional limitation, or disability does not exist" (IOM, 1997, p. 67-70).

A second shortcoming of the 1991 IOM model was "its limited characterization of the environment and the interaction of the individual with the environment" (IOM, 1997, p. 67). While the text of the 1991 IOM report did discuss the importance of the environment in a fair amount of detail, the environment "is not clearly represented in the model except

c. Types of predication in the conceptual components

Since the key conceptual terms, their definitions, and their usages are the same in both the IOM-1 and IOM-2, the types of predication involved in each conceptual component are also the same. The arguments advanced in the corresponding subsection of the discussion of the IOM-1 model will thus apply, *mutatis mutandis*, to the IOM-2 model as well.

D. Social model

1. Background/Overview

The social model of disability takes on a variety of forms in the hands of different theorists (Shakespeare et al, 2006; Shakespeare, 2006, Ch. 2). Consequently, it is more difficult to "pin down"; there is no *single* 'social model.' One introductory overview provides a taxonomy that divides the field into four major versions of the model—the "minority group model," the "barriers model," the "social oppression model," and the "relational model," respectively (Shakespeare et al., 2006, pp. 1103-1105).

The Americans with Disabilities Act (1990) represents one strand of social model thinking, according to which the disabled constitute an oppressed minority, who suffer discrimination at the hands of a society that excludes and marginalizes them. This is the "minority group" version of the social model. Another major strand of social model theories emphasizes the role of social structures, constructed physical barriers, and the like, in creating conditions that preclude the full participation of the disabled in the life of the community. Represented most prominently by Disabled People's International (DPI; see below for further discussion), this is what has been called the "barriers" version of the social model. Many social model theorists, of course, combine elements of these two approaches. Indeed, as Shakespeare et. al. (2006, p. 1104) observe, "[i]n practice, the distinction between the 'barriers' and 'minority group' versions of the social model is not clear."[29]

---

as a category of risk factors involved in the transition between the various categories of the disabling process" (IOM, 1997, p. 60). To rectify this shortcoming, the drafters of the 1997 IOM report elaborate further on the sorts of environmental factors—categorized as (1) "psychological and social environments," and (2) "physical environments," respectively—that can play a role in moving the individual in one direction or the other along the spectrum of the enabling-disabling process.

[29] Moreover, as these authors also note, "the implicit combination of 'barriers' and 'minority group' approaches within most social models [conceals] tensions. In policy terms, should political action be directed at removing structures

The DPI version of the social model is a close cousin of what has been termed the "social oppression" version of the model. Originally formulated in 1976 by the Union of Physically Impaired Against Segregation (UPIAS; see below for further discussion), and more widely popularized in the work of Michael Oliver (1990), this version of the social model has, along with the DPI version, enjoyed ascendancy in British disability studies; in fact, the two versions are typically lumped together under the rubric of the "British social model." These versions of the social model have been enormously influential in the UK context—indeed, to the point of being a "leitmotif" (Thomas, 2002) of, or even a "litmus test" (Shakespeare et al., 2006) for, the field of disability studies in Britain. By contrast, the minority group model, as conceptualized by Harlan Hahn (1988) and others, has been dominant in the United States context. Finally, a "relational" version of the social model has been developed primarily in the Nordic countries (Shakespeare et al., 2006, pp. 1103-1105).[30]

All of these versions of the social model are similar to one another, sharing commonalities in ideas and commitments, varying primarily in their specific details and emphases. For that reason, we shall often speak simply of "the social model," drawing attention to specific formulations only as needed. Nevertheless, it is worth noting in this context that the British social model goes further than other models, by explicitly *redefining* disability with/as (social) "barriers and oppression," rather than defining disability with reference to, or in terms of, impairment (as is the case with other versions of the social model). This has led to a controversy among disability advocates over the use of the term 'persons with disabilities' versus 'disabled people', with British disability advocates preferring the latter as a way of emphasizing that people

---

and barriers to promote equality of opportunity, or should it be directed at benefits and protections for a disadvantaged class of individuals?"

[30] In the Nordic context, theorists have been particularly influenced by the notion of 'normalization,' which finds its roots in the deinstitutionalization movements of the 1970s and the theoretical work of Wolf Wolfensberger (1972) on "social role valorisation." With these influences as background, Nordic theorists have developed a conceptual term – *funksjonshemming* – for 'disability' which emphasizes neutrality regarding "whether the obstacle is in the person or the environment" (Shakespeare, 2006, p. 25).

Citing Tøssebro (2004), Shakespeare (2006, p. 5) identifies the following as "core features of the Nordic relational approach":

1. A disability is a mismatch between the individual and the environment. This occurs both because of individual differences, and because the environment is not adapted to accommodate the range of people. A deaf person is thus not disabled in a setting where everyone speaks sign language.
2. A disability is also situational. A person with a visual impairment is not disabled when using the telephone. Whether a specific individual limitation becomes disabling or not is linked to concrete situations.
3. A disability is relative, a continuum rather than a dichotomy. The cutoff point in impairment-based disability definitions is to some extent arbitrary.

are "disabled by society." By contrast, "activists in most other English-speaking countries favor the term *people with disabilities*—to signal that functional limitation is only one aspect of a person's overall identity" (Shakespeare et al., 2006, p. 1104).[31]

2. Conceptual components

Because there are a number of different versions of the social model, we must of necessity focus our analytical attention here on a representative sample or two. For our purposes, we will devote our attention to the two most prominent versions of the "British social model," in part because of their significant influence on the field of disability studies, and also because they offer explicit definitions of their key conceptual terms, a feature not always found elsewhere in the social model literature.

In sharp contrast to the other models considered earlier in this chapter, the social model (as developed in Great Britain) features only two conceptual components: impairment and disability. On this model, individuals *have* impairments, and they *are disabled* by society—and that is the end of the story. In 1976, for example, the Union of Physically Impaired Against Segregation (UPIAS) proposed the following distinction between 'impairment' and 'disability':

- **Impairment**: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body
- **Disability**: The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976, pp. 3-4, cited in Barnes & Mercer, 2003, p. 11).

The UPIAS definition of 'disability' was clearly influenced by Marxist philosophy and was premised on the notion that "disability should be defined as the relationship between people with impairments and a society that excludes them" (Shakespeare, Bickenbach, Pfeiffer, & Watson, 2006, p. 1103).

---

[31] As Shakespeare (2006) observes, the social model of disability has been developed, in the British context, against the backdrop of two key "taken-for-granted" assumptions—namely, the assumption of a binary, dichotomous relationship between the "medical" and "social" models, on the one hand, and between 'impairment' and 'disability', on the other. By contrast, most non-British disability research has not proceeded on the basis of these two assumptions—and, consequently, has been treated as presumptively suspect by British disability scholars (p. 10). The practical effect, Shakespeare says, has been an ossification of the British social model into a "rigid ideology" that insists that disability has to do exclusively with social barriers, and has "nothing to do with individual impairment" (p. 10).

Similarly, in 1982 Disabled People International (DPI) proposed that the distinction between these two terms be cashed out in the following way:

- **Impairment**: 'the functional limitation within the individual caused by physical, mental, or sensory impairment'.
- **Disability**: 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (DPI, 1982, cited in Barnes & Mercer, 2003, p. 66).

It should be noted that the DPI formulation has come into criticism for two "logical flaws" inherent in the definitions given above. First, the definition of 'impairment' is blatantly circular: impairment is defined in terms of itself, as a "functional limitation... caused by... impairment." Second, and arguably more significant, the definition of "disability" makes no reference to "impairment" as a necessary condition for disability. This was intentional on the part of DPI—their intention was to "decouple disability from impairment" (Shakespeare et al., 2006, p. 1104). The (perhaps unintended) consequence of this, however, was that "impairment ceases to be a qualification for being a disabled person," as a result of which "other social groups—such as people who experience racism or sexism or poverty—could be included within the social model definition, even if they do not have impairments" (Shakespeare et al., 2006, p. 1104). In effect, then, the DPI definition of 'disability' is arguably so broad as to include within its ambit many who would not otherwise have been considered disabled—which, in turn, has the potential to undercut significantly the conceptual power of the theoretical framework proposed by the DPI, not to mention its rhetorical and/or political force.

3. Constrained versus unconstrained social models

At this point, it is necessary to introduce yet another distinction into our discussion, one that will prove significant as this work progresses. The distinction in view here is that between what we might term "constrained" and "unconstrained" versions, or general types, of the social model. The distinction turns on what each of these types of social model says about the nature of *impairment* (as opposed to their views on the nature and cause of *disability,* as discussed above). On the one hand, we see a "constrained" version of the model, one that is based upon and

accepts a realism regarding impairments. On the other hand, we see an "unconstrained" version of the model, one that is based on a Foucaldian nomimalism[32] about impairments, according to which there is no meaningful distinction to be made between "impairment" and "disability," by virtue of the fact that *both* terms are the product of a social construction. On this latter view, *neither* term falls under any biological constraints at all—a crucial feature of social construction of the Foucauldian variety. This is, of course, the realism versus nonrealism debate, as applied to the question of the nature of impairment and disability. On the one hand, some social model theorists acknowledge the objective reality of biological (physiological, anatomical, etc.) impairment, and do not attempt to downplay either its significance or its very real impacts on human functioning (apart from the further question of what additional impacts might *also* be brought about by environmental—especially sociocultural—factors). Other, more "radical" social model theorists insist that impairment is just as a much a "social construction" as is disability[33]—that is, what we refer to as "impairments" turn out to be (nothing but) *labels* we use to identify (and marginalize) modes of functioning that are *disfavored* or *disvalued*—despite the fact that they are, in reality, merely "different" modes of functioning. Thus, for example, if the majority population functions in a particular way in a particular context—say, walking without mechanical assistance—then the majority *labels* a "non-walker" (say, someone who uses a wheelchair)

---

[32] Nominalism is a philosophical thesis about the nature of *universals,* that is, those features of objects that are shared by—or are capable of being shared by—multiple, perhaps even "indefinitely many," objects (Lacey, 1986, p. 253)—e.g. the property of 'being round,' or 'being square,' or 'being a dog.' The philosophical puzzle is how such features ought to be characterized—do they exist in their own right, as "objects" of a certain sort, or is their ontological status such that it can be reduced to some other notion? For example, does "doghood" exist as an entity in its own right, or only in specific instances of dogs? To put it differently, do universals exist *only* in their "particulars," or do they *also* exist independently of their particulars? According to nominalism, "there are only general words like 'dog', and no universals in the sense of entities like *doghood*" (Lacey, 1986, p. 254). Nominalism is frequently contrasted with essentialism, "the doctrine that at least some objects have essences" (Lacey, 1986, p. 50), as well as with realism: "Any view can be called realist which emphasizes the existence, or role, of some kind of thing or object (e.g., material objects, propositions, universals), in contrast to a view which dispenses with the things in question in favour of words (nominalism)..." (Lacey, 1986, pp. 200-201).

Most relevantly for present purposes, nominalism can be applied specifically to the question of the ontological status of properties. In this regard, George Bealer helpfully lays out the range of positions on this issue as follows:

> Because properties are a kind of universal, each of the standard views on the ontological status of universals has been applied to properties as a special case. *Nominalism:* only particulars (and perhaps collections of particulars) exist; therefore, either properties do not exist or they are reducible (following Carnap et al.) to collections of particulars (including perhaps particulars that are not actual but only possible). *Conceptualism*: properties exist but are dependent on the mind. *Realism*: properties exist independently of the mind. Realism has two main versions. *In rebus* realism: a property exists only if it has instances. *Antes rem* realism: a property can exist even if it has no instances. For example, the property of being a man weighing over [a] ton has no instances; however, it is plausible to hold that this property does exist. After all, this property seems to be what is expressed by "is a man weighing over a ton" (Bealer, 1995, p. 657).

[33] Consider, for example, Michael Oliver, who claims that "[i]t is not individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization" (Oliver, 1996, p. 32, quoted in Shakespeare, 2006, p. 38).

"impaired." On this view, it is not the case that a person who is unable to walk without mechanical assistance is *in fact* impaired[34]—rather, "impairment" is the term the majority uses to refer to a non-standard (and disvalued) way of functioning (in this case, using a wheelchair). This version of the social model is thus "nominalist" (or Foucaldian) rather than "realist" regarding impairment—or, put differently, "unconstrained" rather than "constrained." We will have occasion later in this work to return to this distinction and the ideas underlying it; indeed, in chapter 2, we will develop an explicit critique of the "unconstrained" version of the social model. For now, however, the main point is simply to make the reader aware of this important conceptual nuance that must be taken into account when discussing the social model of disability.

4. Types of predication in the conceptual components

In considering whether the social model involves predications of intrinsic constitutive properties or predications of judgment, it is important to keep in front of us the distinction just brought out, between "constrained" and "unconstrained" versions of the social model. As we noted, on a constrained social model the objective ontological reality of impairment is acknowledged, whereas an unconstrained social model denies the objective ontological reality of impairment as a natural feature of the world (or, more precisely, of the bodies of those who have them).

Consistent with this distinction, it would seem that an unconstrained social model must, of necessity, consider *both* impairment *and* disability as strictly extrinsic/"relational" predicates—that is, predications of judgment, rendered on the basis of facts about the relationship between the individual and society, rather than predications of intrinsic constitutive properties of the individual. Given the unconstrained social model's commitment to the notion that "social construction" goes "all the way down"—encompassing both 'impairment' and 'disability' in its ambit—it would seem that this version of the social model cannot do otherwise than deny altogether *any* predication of intrinsic constitutive properties.

By contrast, a "constrained" social model, while affirming a role for social values and practices in "constructing" disability, can nevertheless allow conceptual room for some sense in

[34] Thus, for example, Barry Allen claims that "nobody is impaired all on her own, through a naturally occurring deficit that her body bears as a biophysical property" (Allen, 2005, p. 94, quoted in Reinders, 2008, pp. 77-78).

which 'impairment' involves the predication of an intrinsic constitutive property to the individual, whereas 'disability' involves a relational, or extrinsic, predication of judgment.

Arguably, the two social model formulations quoted above exemplify this latter understanding of the predications involved in each of the key conceptual components. Notice, for example, that in defining the term 'impairment,' the UPIAS formulation refers exclusively to "[l]acking part or all of a limb, or having a defective limb, organ or mechanism *of the body*" (UPIAS, 1976, pp. 3-4, cited in Barnes & Mercer, p. 11; italics added)—no reference is made to anything (e.g., society) outside the individual and her body. By contrast, the UPIAS definition of 'disability' refers explicitly to the role of society in causing disability—indeed, disability itself is characterized as "disadvantage" or "restriction" (rather than a bodily state of some sort), which state is "*caused by* a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1976, pp. 3-4, cited in Barnes & Mercer, p. 11; italics added). The DPI formulation quoted above follows a similar pattern. Aside from its blatant circularity ("impairment" is defined in terms of "impairment"), the crucial thing to notice about the DPI definition is that it refers exclusively to functional limitation "*within the individual*"—here again, no reference is made to anything outside the individual. By contrast, again, the DPI formulation of 'disability' explicitly defines the concept in relational terms: disability is characterized as "loss or limitation of opportunities" that is directly caused by ("due to") "physical and social barriers"—features that are inevitably relative, or *extrinsic,* to the individual, rather than intrinsic to her (DPI 1982, cited in Barnes & Mercer, p. 66).

Relying as they do on a strict impairment/disability distinction, most "social model" theorists are best characterized as being "constrained" vis-à-vis the ontological reality of impairment. As we saw above, however, there are some who deny the objective ontological reality of impairments—and, hence, can be called "unconstrained" social model theorists. Such theorists can be seen as positing strictly *extrinsic* predications "all the way down"—that is, as saying that 'impairment' is as much a predication of judgment as is 'disability.' On this

"unconstrained" social model account, then, both impairment and disability are construed as involving predications of judgment rather than predications of intrinsic constitutive properties.

In order to avoid confusion, a word of clarification is in order here. We observed earlier that the British social model—as exemplified by the UPIAS and DPI formulations—are notably more "radical" than other versions of the social model, in that they explicitly *redefine* 'disability' as (or in terms of) social oppression, rather than as a condition that is (in some sense) grounded in impairment.[35] Importantly, however, the "radical" view that redefines *disability* in terms of social oppression or barriers is nonetheless consistent with a "constrained" view regarding *impairment.* That is, one might characterize *impairment* as being an objective (ontological) reality, while nevertheless characterizing *disability* exclusively in terms of social oppression and barriers, as we saw with the UPIAS and DPI formulations above. Or, alternatively, one might argue that *both* 'impairment' and 'disability' are *nothing but* social constructions. We have presented here an interpretation of the UPIAS and DPI formulations as exemplifying the former approach, in which case we can coherently refer to these models as "radical" in one sense, while "constrained" in another: "constrained" in the sense of acknowledging the objective reality of impairment, while "radical" in the sense of redefining disability as social oppression. Conceptually, both of these can co-exist in the same model of disability, and it is this nuance (among others) that makes discussions of "social models" of disability especially slippery.

In light of the foregoing, we can plausibly generalize regarding what the social model has to say about the types of predications involved in each of its constitutive terms. Briefly, we can say that for a "constrained" social model, "impairment" involves the predication of an intrinsic constitutive property to an individual, whereas "disability" involves a predication of judgment based on the relationship between the individual and her surrounding society. By contrast, the "unconstrained" social model casts both impairment and disability as involving (only) relational, or extrinsic, predications—that is, predications of judgment.

---

[35] What makes this a approach a "radical" one, according to Wasserman et al., is that "[o]n this definition, disability in effect loses its grounding in biological dysfunctions in the individual and becomes entirely a matter of the social reception of perceived human difference" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 13). Disability then becomes merely, or nothing but, "a disadvantage resulting from discrimination and related invidious and unjust social responses" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 13).

E. *International Classification of Functioning, Disability, and Health* [ICF/ICIDH-2] (WHO, 2001)

1. Background/Overview

In contrast to the ICIDH, which focuses on impairment, disability, and handicap conceived as "consequences of disease," the ICF has a "components of health" emphasis, placing functioning and disability under the rubric of "health conditions" (WHO, 2001, p. 5). On the ICF, "[d]isability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives" (WHO, 2001, p. 20). Strictly speaking, the ICF is a *classification scheme* rather than a *model* of disability. Thus, one can conceive of a variety of potential relationships between the various elements of the classification scheme, and the scheme is designed so as to facilitate further scholarly research of this sort. The overall approach of the ICF is a "multi-perspective," "multidimensional" one that is premised on a "dynamic," two-way interaction between the various elements (i.e., impairment, disability, etc.) (WHO, 2001, p. 22). As such, the ICF is explicitly intended to be understood as an attempt to "synthesize" the medical and social models of disability, taking from each model what is best about them, while avoiding their respective weaknesses. The framers of the ICF refer to this as a "biopsychosocial approach" to understanding disability (WHO, 2001, pp. 24-25).

2. Conceptual components

Compared to the other models under consideration in this work, the ICF employs a unique set of conceptual components: (1) health context, (2) body function/structures/impairment, (3) activity/activity limitation, (4) participation/participation restrictions, and (5) contextual factors (environmental & personal).[36]

---

[36] The ICF is intended to have universal application to all human beings. However, recognizing that human "well-being," or flourishing, encompasses much more than health—the specification of which would go well beyond the scope of what any single classification scheme could hope to capture—the explicit focus of the ICF framework is on "health domains" and "health-related domains" as specific components of "well-being" (WHO, 2001, pp. 8-10). More specifically, the focus is on human functioning and its restrictions, as seen in "body functions and structures" and "activities and participation," on the one hand, in dynamic interaction with personal and environmental "contextual factors," on the other. "Functioning" and "disability" are interpreted in terms of *changes* in physiological systems and/or anatomical structure, while "activities and performance" are measured in terms of an individual's *capacity* (in a standard environment) or her actual *performance* (in her current environment). Environmental and personal contextual factors can interact at every point along the way—that is, with any or all of body functions and structures, activities, and participation. Environmental factors are conceived as features of the "physical, social, or attitudinal world" that have either a hindering

In the ICF, "disability" serves as an "umbrella term," encompassing the entire "disablement process" (what the ICIDH separated into "impairment," "disability," and "handicap," respectively) which results in decrements of functioning specified in terms of impairments, activity restrictions, and/or participation restrictions. Given its role as an umbrella term, "disability" as such is not explicitly defined in the ICF. Nevertheless, the framers of the ICF come close to offering an explicit definition of the term when they state that "[d]isability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives" (WHO, 2001, p. 20). Thus characterized, disability is pictured as a dynamic, interactive process involving (inter-) relationships between a variety of factors (biological, psychological, personal, social, etc.).[37]

The key conceptual terms used by the World Health Organization in developing the ICF's framework are defined as follows:

In the context of health:

Body functions are the physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body such as organs, limbs, and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

---

or facilitating effect on an individual's activities and/or participation (measured either in terms of capacity or actual performance). The importance of personal environmental factors is also noted, but such factors (because they are so numerous and variable) are not explicitly classified in the ICF (WHO, 2001, pp. 8-10).

Structurally, the classification scheme is divided into two main "parts," each of which consists of two distinct "components." The components, in turn, are divided into two "domains," which are then interpreted in terms of specific "constructs." Depending on whether the "positive aspect" of functioning or the "negative aspect" of disability is being measured, the above classifications yield information regarding "functional and structural integrity," "activities and participation," "impairment," and/or "activity limitations" and "participation restrictions."

[37] The IOM has recently endorsed the ICF's "interactive" model of disability—concluding that "disability is not an inherent attribute of the individual but, rather, is the result of the interaction of the individual with the environment, including social norms" (IOM, 2007)—and has encouraged its use as the international standard for measurement and discussion of disability henceforth. Whether this is intended to be an abandonment of, or merely a supplement to, the IOM'S own models of disability is unclear.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives (WHO, 2001, p. 10, bold in original).

a. Health context

In contrast to the ICIDH, the ICF seeks to place all discussions of 'disability' (and other related terms) under the conceptual rubric of "health context." The basic idea here is that a given health condition can result in impairments, which then result in either activity limitations or participation restrictions, or both. For example, given a "health context" of leprosy, the associated impairment would be "loss of sensation of extremities," which may in turn lead to activity limitations—e.g. "grasping difficulties"—and/or participation restrictions, such as being "denied employment because of stigma" (WHO, 1998, cited by Altman, 2001, at p. 104). The motivation behind this shift in terminology (from the ICIDH to the ICF) was largely an attempt to respond to criticisms of the ICIDH model, namely, that it was too beholden to, or reflective of, the "medical" model of disability. Here, the framers of the ICF are attempting to account for a broader range of dimensions (activity, social, etc.) in terms of which impairments can have limiting effects on those who have them.

b. Body function/body structures/impairment

In the ICF, 'impairment' is now placed under the rubric of "body function and structure," and is described as "problems in body function or structure as a significant deviation or loss" (WHO, 1999, p. 16, quoted in Altman, 2001, p. 105). (Here, "body" is construed broadly to include "the whole human organism, including the brain and its functions" [Altman, 2001, p. 105].) The "deviation" in question is in reference to "generally accepted population standards," which standards are "...to be arbitrated by 'those qualified to judge physical and mental functioning according to generally accepted standard (*sic.*)'" (WHO, 1999, p. 16, quoted in Altman, 2001, p. 105). What this implies, Altman observes, is that "such judgments are carried out by professionals, are outside the person's own experience with the impairment, and are based on a

group standard rather than the person's capabilities prior to the impairment" (Altman, 2001, p. 105).

The ICF recognizes a "biological foundation" for impairments. Moreover, as noted in the previous paragraph, impairments are identified in terms of "population standards"—that is, the population "norm" constitutes the reference point for identifying impairments (WHO, 2001, p. 14). Importantly, on the ICF, 'impairment' is a "broader and more inclusive term" than is either 'disease' or 'disorder'—that is, while some diseases and disorders also involve impairments, not all impairments involve disease or disorder ("for example, the loss of a leg is an impairment of body structure, but not a disorder or a disease") [WHO, 2001, p. 15]. Impairments are classified as such on the basis of certain "identification criteria," where those criteria involve the determination of whether or not a condition has passed a given "threshold level," that is, whether the condition is "present" or "absent" in terms of that criterion. So understood, impairments fall into four broad categories: (1) "loss or lack," (2) "reductions," (3) "addition/excess," and (4) "deviation" (WHO, 2001, p. 16).

c. Activity/activity limitation

In the revised version of the ICIDH—i.e., the ICF—the singular term 'disability' is delineated further, in an attempt to achieve greater clarity and specificity in terminology, and (as noted previously), the term 'handicap' is dropped altogether. The 'disability' concept is now given two foci: limitations with respect to activities ("activity/activity limitation") and limitations with respect to (social) participation ("participation/participation limitation"). These two foci constitute the ICF'S "third component" and "fourth component," respectively. Here again, a distinction between levels is observed—this time, a distinction between the *mechanism* level, reflected in the ICIDH-2's reference to "body functions/body structures/impairment" (second component), and the *person* level, as seen in its treatment of the "activity/activity limitation" dimension (third component) [Altman, 2001, p. 107].[38]

The ICF's third component, "activity/activity limitation" is, in turn, defined as "the performance of a task or action by an individual' (WHO, 1999, p. 19, quoted in Altman, 2001, pp.

[38] See note # 13 for more regarding "levels."

107-108). Here, the emphasis is on "the performance of the task" itself, whereas the fourth component—"participation/participation limitation"—focuses on the individual's level of involvement in a given life area (typically requiring the "task" in question), "particularly whether involvement is restricted or facilitated" by "barriers" or "facilitators" (WHO, 1999, p. 19, cited in Altman, 2001, pp. 107-108).

d. Participation/participation limitation

Where the ICIDH-1 speaks of "handicap," the ICIDH-2 speaks of "participation/participation limitation," defined as "an individual's involvement in life situations in relation to health conditions, body functions and structures, activities and contextual factors" (WHO, 1999, p. 19, quoted in Altman, 2001, p. 109). That is to say, the "participation" dimension seeks to measure the degree to which an individual, given a particular health condition, impairment, activity limitation, and environmental/personal context, is able to *participate* in social life. This judgment is made in comparison to a person who does not have the same sort of "activity limitation" as does the individual being evaluated (Altman, 2001, p. 109-110).

e. Context: environmental & personal

The ICF adds a fifth component, namely "contextual factors," which in turn are divided into "personal" and "environmental." These factors

> represent the complete background of an individual's life. Contextual factors are made up of personal factors, reflecting an individual's background, and environmental factors represented by the physical and material features of the person's environment, the available formal and informal social structures and services in the community, and the overarching systems established in a culture (Altman, 2001, p. 110).

The classification scheme does not specify "personal factors," but it does break "environmental factors" down into further subcategories, such as "individual environments (including home, workplace, and school), service systems available in the community, and cultural systems (including laws as well as attitudes)" (Altman, 2001, p. 110).

3. Types of predication in the conceptual components

Characterizing the types of predication involved in the conceptual components of the ICF model involves a two-step process. First, we need to review some of what we said about each of the individual conceptual components identified above, this time with a view toward identifying the types of predications involved in each case. Then, in recognition of the fact that the ICF does not explicitly define "disability" as such—but, rather, conceptualizes disability as an "umbrella term" that encompasses other conceptual terms, specifically 'impairment' 'activity limitation', and 'participation limitation'—we need to aggregate our findings with respect to each of these individual conceptual components, to see what we can infer about the type of predication involved in the ICF's notion of "disability" (understood as an umbrella term). To this two-stage process we now turn our attention.

a. Impairment

As noted above, the ICF explicitly recognizes a "biological foundation" for impairments. Whereas in the ICIDH, "impairments" are conceptualized as being located at the "organ" level, in the ICF they are subsumed under the "body structures" heading (WHO, 2001, p. 14), and are described as "problems in body function or structure as a significant deviation or loss" (WHO, 1999, p. 16, quoted in Altman, 2001, p. 105). So understood, impairments fall into four broad categories: (1) "loss or lack," (2) "reductions," (3) "addition/excess," and (4) "deviation" (WHO, 2001, p. 16). In all these characterizations, no reference is made to features outside of the individual; hence, it seems reasonable to conclude that the framers of the ICF intended 'impairment' to be understood as involving predications of *intrinsic constitutive properties*.

b. Activity limitation

The ICF's third component, "activity/activity limitation" is defined as "the performance of a task or action by an individual' (WHO, 1999, p. 19, quoted in Altman, 2001, pp. 107-108). Although, as we saw above, the notion of "activity limitation" is cast by the ICF as appearing at the level of the *person* rather than at the mechanism-level, nevertheless the emphasis is on the performance of the *task* itself *by the person*. The focus is on those features of the individual that make it possible—or not—for her to perform a given task. Consequently, it seems reasonable to

conclude that the 'activity limitation' component of the ICF framework is intended by its framers to be understood as involving the predication of *intrinsic constitutive properties.*

c. Participation limitation

By contrast, the ICF's fourth component, "participation/participation limitation"—defined as "an individual's involvement in life situations in relation to health conditions, body functions and structures, activities and contextual factors" (WHO, 1999, p. 19, quoted in Altman, 2001, p. 109)—focuses on the individual's *level of involvement* in a given life area (typically requiring the "task" in question), "particularly whether involvement is restricted or facilitated" by "barriers" or "facilitators" (WHO, 1999, p. 19, cited in Altman, 2001, pp. 107-108). This conceptual component thus seeks to measure the degree to which an individual, given a particular health condition, impairment, activity limitation, and environmental/personal context, is able to *participate* in social life. This judgment is made in comparison to a person who does not have the same sort of "activity limitation" as does the individual being evaluated (Altman, 2001, p. 109-110), and is thus clearly a *relational* attribute involving a *predication of judgment* rather than of intrinsic constitutive properties.

d. Disability

Given the foregoing, we can now draw the inferential conclusion that 'disability' is conceptualized on the ICF in *both* intrinsic *and* extrinsic (relational) terms. To see how this is the case, recall that on the ICF, 'disability' is an "umbrella" term, encompassing impairments, activity restrictions, and participation restrictions. We showed in the preceding paragraphs that 'impairment' and 'activity limitations' are best understood as involving intrinsic predications, while 'participation restrictions' appear to involve relational, or extrinsic, predications. If this analysis is correct, then it seems we can draw the following conclusion: if disability is an umbrella term that encompasses impairments *and* restrictions (of activity and/or participation), and if both impairment and activity limitations have reference to intrinsic features but participation limitations refers to extrinsic/relational features, then the larger "umbrella" category—disability—must, of necessity, involve *both* intrinsic *and* extrinsic predications.

III. RELATIONSHIPS AMONG THE MODELS OF DISABILITY: A SUMMATIVE COMPARISON

It is time now to begin pulling together the different theoretical threads we have been pursuing over the course of this chapter. We want to end up with a broad understanding of how the various models of disability we have examined in this chapter relate to one another conceptually, and to get at least a start at understanding some of the implications that these relationships might have for the larger project in which this work is engaged. One way to approach this task is by recalling the two central questions about disability that we mentioned in the Introduction —namely, "what is disability?" and "what causes disability?"—and then to consider how the models we have looked at relate to one another in terms of their answers to these questions.

Turning first to the question, what *is* disability?, we saw that this question is answered in different (but related) ways by the various models under consideration. For Nagi, disability is a "pattern of behavior." On the ICIDH, disability is a restriction or lack of ability. For Verbrugge and Jette disability involves "difficulty doing activities of daily living," and is characterized in terms of a mismatched relationship between "capacity" and "demand." The two versions of the IOM model characterize disability as an inability to perform socially expected tasks and roles, which results from a "complex interaction" of risk factors (biological, behavioral, environmental) and quality of life. The social model advanced by Disabled Peoples' International (DPI) defines disability in terms of a loss or limitation of opportunity for equal participation (in society), whereas UPIAS casts disability as "disadvantage or restriction of activity" caused by an exclusionary organization of society. Finally, although the ICF does not include an explicit definition of disability as such, it does view "functioning" and "disability" as "umbrella terms," where "disability" encompasses the processes represented by the terms 'impairment,' 'disability,' and 'handicap,' and is characterized in terms of decrements or limitations in "activity" and/or "participation."

Our explorations in this chapter also revealed divergent answers to the question, what is the *causal locus* of disability (or, more concisely, what *causes* disability?). As Altman (2001, p. 113) explains, the Nagi framework can be interpreted as telling more than one causal story. On

the "standard" view, pathology causes impairment, which in turn causes functional limitation, which then causes disability; an "alternative" reading of the Nagi framework sees pathology, impairment, and functional limitation as being mediated by "role interactions," as a result of which interactions disability may—or may not—result. On the ICIDH, disease (understood as a manifested pathology) causes impairment, which can then cause disability, which can, in turn, cause handicap. Alternatively, on the ICIDH, disease may cause impairment, which can then directly cause handicap (e.g., when an individual is *perceived* as being disabled by an impairment, and is therefore disadvantaged socially, even though she is not *in fact* disabled. On the Verbrugge/Jette model (which the authors refer to as a "sociomedical model" of disability), the "main pathway" in the "disablement process" involves a progression from pathology to impairment to functional limitation and on to disability. Importantly, however, Verbrugge and Jette picture this "main pathway" as potentially being interrupted and/or enhanced by "interventions" and/or "exacerbators," respectively. Both versions of the IOM model, as we noted in the previous paragraph, characterize disability as an inability to perform socially expected tasks and roles, and trace that inability causally to a "complex interaction" between various risk factors (biological, behavioral, environmental) and "quality of life." On the ICF, "disability" is understood in terms of decrements or limitations in activity and/or participation, which limitations/restrictions are brought about, in part, by a combination of personal and environmental factors interacting with changes in body function (physiology) and structure (anatomy). Finally, on both the UPIAS and DPI versions of the social model, disability is caused by society—that is, by social oppression and/or neglect, discrimination, barriers, etc.

Another way of approaching the task at hand is to compare and contrast the various models discussed in this chapter in terms of their respective characterizations of the key conceptual components of which they are comprised. Specifically, we can query, with respect to each conceptual component, whether it is characterized as being an "intrinsic" or "extrinsic" property (or, perhaps, both). That is, with respect to a given conceptual component, we can ask what the model in question is *saying* about that component as it relates to the individual in question. Thus, for example, when a given model speaks of 'impairment,' is it saying that

'impairment' is a property that is *present in,* or part of, the individual's *constitutive identity*—i.e., an "intrinsic" property? Or is 'impairment' something that is merely *said of* the individual—i.e., a predication of judgment rather than of an intrinsic constitutive property?

With respect to this question, we can summarize our findings in this chapter as follows (see Table 1.2 at the end of this chapter for a visual representation of this summary). For the Nagi model, 'pathology,' 'impairment,' and 'functional limitations' involve predications of *intrinsic* properties, whereas 'disability' involves the predication of an *extrinsic* (relational) property. The same taxonomy is arguably true of the Verbrugge/Jette and the IOM models. The terminology employed by the ICIDH is slightly different, but the types of predications involved appear to follow the same pattern as in the Nagi, Verbrugge/Jette, and IOM models—that is, 'impairment,' and 'disability' appear to involve predications of *intrinsic* properties, whereas 'handicap' appears to involve the predication of an *extrinsic* (relational) property. In the ICF, 'impairment' and 'activity limitation' seem to involve an *intrinsic* predication, 'participation limitation' appears to involve *extrinsic* predication, and 'disability' appears to involve *both* intrinsic *and* extrinsic (relational) predication. Finally, when considering the kinds of predications made by the social model, we must distinguish between the "constrained" and "unconstrained' versions of the model. Arguably, on the constrained social model, 'impairment' is an objectively real, *intrinsic* property of the individual in question, whereas 'disability' is an *extrinsic* property involving the (socially-constructed) relationship between the individual and society. By contrast, given its commitment to social construction "all the way down," it would seem best to understand the unconstrained social model as seeing *both* impairment *and* disability as strictly *extrinsic* (relational) properties.

Thus, we see that nearly all the models examined in this chapter follow virtually the same pattern—namely, they affirm one or more *intrinsic* components *and* also affirm, as their "outcome" term, an *extrinsic* component. The specific terminology, and their relative places in the models, differs from model to model; however, the important point for present purposes is that these models follow a *both-and* pattern: they affirm *both* intrinsic and extrinsic property predications (or attributions). Just one model—the unconstrained social model—rejects the *both-and* pattern in favor of an insistence that *only* extrinsic predications are involved. We will see later how this gives

us reason to question the viability of the unconstrained version of the social model. For now, however, it is sufficient simply to take note of these similarities and differences among the various models under consideration in this chapter.

A third way of approaching the task to which this section is devoted is to consider the question, at what level does normativity enter into each of the models under consideration—that is, to what extent does the characterization of each of the various conceptual components make reference to, or rely upon, a *norm* of some sort, as opposed to being characterized in value-neutral, or non-normative ways? In this regard, we saw that normativity frequently enters into models of disability, and at various levels. In some cases, the appeal is explicit; in others, it is implicit. In the discussion of each of the models above, we have highlighted at relevant points the intrusion of normativity into the characterization of each of the key conceptual terms; for that reason, we will not rehearse the case for each of these in the present context. The important point for now is to emphasize the central role of normativity in conceptualizations and modeling of disability; we will have more to say about this as the work progresses.

IV. CONCLUSION

The overall strategy of this chapter has been to arrive, through close textual analysis, at three key elements, which are summarized in Table 1.2. First, we have sought to identify the main conceptual components of certain representative models of disability. Second, with respect to each of those components, we have sought to characterize how they are *conceptualized*—that is, whether they are characterized as involving the predication of *intrinsic* or *extrinsic* properties, and how they answer the two key questions (what? why?) about disability. Third, we have sought to demonstrate that normativity (i.e., implicit and/or explicit appeals to norms of various sorts) enters into these specific models of disability at various theoretical levels.

In the context of this present work, the significance of this chapter's analysis is that it helps to set the stage for subsequent explorations in which the work will be engaged. As indicated previously, this work aims to move from particular accounts of disability—the models discussed in this chapter—to more generalized accounts of disability, with a view toward identifying what kinds of general, trans-model conclusions we can draw about the nature of

disability. This represents a sort of "bottom-up" approach, according to which we begin at the level of individual conceptual components ('impairment', 'disability', 'handicap', etc.) and move upward toward more and more generalized accounts that seek to answer the two key questions we identified earlier—namely, "what is disability?" and "what causes disability?"

In the next chapter, we turn our attention to the *general approaches* to modeling disability—the moral, medical, and social model approaches—with a view toward understanding their respective commitments regarding impairment and disability. This is important because it helps us to move from specific to general, since our larger goal is to arrive at an overall, generalized analysis of "the concept of disability." The basic thought is that if we can discern relevant similarities and/or dissimilarities among the general types of approaches to modeling disability, this may help us in generalizing to such a broader concept of disability.

Based on the findings of this chapter, we are now in a position to draw the following two general conclusions. First, disputes about models of disability have to do, in part, with what the models' key conceptual terms are *predicating* of their referents—an intrinsic property? an extrinsic property?—and the alleged implications that are seen to flow from such predications. This is key to understanding the disputes among proponents of different models of disability, especially (as we will see) in the context of the "medical-vs.-social model" debate. Furthermore, given that each of the models we have examined thus far includes at least one term (typically the "outcome term," e.g., disability) that involves extrinsic predication, this gives us *prima facie* reason to think that *any* adequate account of disability will have to include at least one such term.

Second, since normativity appears to enter into models of disability at a variety of theoretical levels—quite possibly at *all* levels—any account that purports to explain disability in strictly non-normative terms will, at the very least, be presumptively suspect. To be sure, we have not yet *established* definitively that disability cannot be characterized in strictly non-normativist terms—that task remains for a later chapter (see chapter 4). However, given the patterns evident in our explorations thus far—specifically, that (1) implicit and explicit appeals to norms appear to enter into models of disability at various theoretical levels, and (2) in the case of each of the models examined thus far, "disability" (or its equivalent) always involves "extrinsic" or relational

predications, thereby requiring a move "beyond" the individual to a consideration of broader social and environmental factors, and implying in turn a comparative appeal to a norm of some sort—we have good reason to suspect that this will turn out to be the case.

Table 1.2 – Conceptualization of Key Terms in the Models, by Type of Predication

Model	*Conceptual Component*	*Definition*	*Type of Predication?*
Nagi	Pathology	A state of mobilization of the body's defenses and coping mechanisms, resulting from infection, metabolic imbalances, traumatic injury, or other etiology	Intrinsic
	Impairment	Anatomical and/or physiological abnormalities and losses, including both conditions associated with pathology (e.g., an amputated limb due to an infection) and conditions not associated with pathology (e.g., congenital deformities)	Intrinsic
	Functional limitation	Limitations—including physical, emotional, intellectual, and sensory—which impairments set on an individual's ability to perform the tasks and obligations of his usual roles and normal daily activities	Intrinsic
	Disability	A pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations	Extrinsic/ Relational
IOM-1 & IOM-2	Pathology	Active disease, i.e., "cellular and tissue changes caused by disease, infection, trauma, congenital conditions, or other agents"	Intrinsic
	Impairment	Losses of mental, anatomical, or physiological structure or function owing to injury, active disease, or residual losses from formerly active disease; "a discrete loss or abnormality of mental, physiological, or biochemical function," including "losses caused by all forms of pathology"	Intrinsic
	Functional limitation	"Effects manifested in the performance or performance capacity of the person as a whole"	Intrinsic
	Disability	Limitations in physical or mental function, caused by one or more or health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do; the expression of a physical or mental limitation in a social context—the gap between a person's capabilities and	Extrinsic/ Relational

		the demands of the environment	
Verbrugge/Jette	Pathology/disease	"Biochemical and physical abnormalities that are detected and medically labeled as disease, injury, or congenital/developmental conditions"	Intrinsic
	Impairment	"Dysfunctions and significant structural abnormalities in specific body systems"	Intrinsic
	Functional limitation	"Restrictions in performing fundamental physical and mental actions used in daily life by one's age-sex group"	Intrinsic
	Disability	Experienced difficulty doing activities in any domain of life due to a health or physical problem	Extrinsic/ Relational
ICIDH	Disease and disorders	A manifested ("exteriorized") pathological condition	Not applicable
	Impairment	"Any loss or abnormality of psychological, physiological, or anatomical structure or function"	Intrinsic
	Disability	In the context of health experience, any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; the effects that impairments may have on the individual in terms of her performance and/or activity	Intrinsic
	Handicap	In the context of health experiences, a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual; "disadvantages experienced by the individual" as a result of either impairments or disabilities	Extrinsic/ Relational (or <u>both</u> – see note # 17)
ICF (ICIDH-2)	Health context	Not defined in ICF	Not applicable
	Body function/body structures/ impairment	**Body functions:** the physiological functions of body systems (including psychological functions) **Body structures:** anatomical parts of the body such as organs, limbs, and their components **Impairments:** problems in body function or structure such as a significant deviation or loss	Intrinsic

	Activity/activity limitation	**Activity:** the execution of a task or action by an individual **Activity limitations:** difficulties an individual may have in executing activities	Intrinsic
	Participation/participation limitation	**Participation:** involvement in a life situation. **Participation restrictions**: problems an individual may experience in involvement in life situations	Extrinsic/ Relational
	Context: environmental & personal	**Environmental factors:** the physical, social, and attitudinal environment in which people live and conduct their lives. **Personal factors**: not defined in ICF	Not applicable
Social model – constrained	Impairment	**UPIAS**: "lacking part or all of a limb, or having a defective limb, organ or mechanism of the body" **DPI**: "the functional limitation within the individual caused by physical, mental, or sensory impairment"	Intrinsic
	Disability	**UPIAS**: limit or loss of opportunities to take part in community life because of oppression/exclusion; "[t]he disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" **DPI**: limit or loss of opportunities to take part in community life because of physical and social barriers; "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers"	Extrinsic/ Relational
Social model – unconstrained	Impairment Disability	On the unconstrained version of the social model, both "impairment" and "disability" are conceptualized as being social constructions. Therefore, they are both understood as involving extrinsic/relational predications	Extrinsic/ Relational

Table 1.3 – Definitions of Disability Derived from the Theoretical Models
(Source: Adapted from Altman, 2006, p. 103, Table 3.2)

Model	Definition of Disability
Nagi	Pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations
IOM-1 and IOM-2	The expression of a physical or mental limitation in a social context—the gap between a person's capabilities and the demands of the environment
Verbrugge/Jette	Disability is experiencing difficulty doing activities in any domain of life due to a health or physical problem
WHO/ICIDH-1 *	In the context of health experience, any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (* = NOTE: There is no entry for the ICF/ICIDH-2 because that model does not define 'disability' as such; instead, disability is recast in terms of activity and participation restrictions/limitations.)
Social model	Limit or loss of opportunities to take part in community life because of physical and social barriers (DPI version) and/or social oppression/exclusion (UPIAS version)

Chapter 2

THE CONCEPT OF DISABILITY: MODELS OF DISABILITY (II)—ASSESSMENT

I. INTRODUCTION

In this chapter we continue with the task of laying out the theoretical background in terms of which our larger analysis of the concept of disability takes place. The "jumping-off point" here is a recollection of the observation made in the previous chapter that the various models discussed all use the same (or very similar) terms—'impairment,' 'disability,' 'handicap,' etc.—yet, just as clearly, these terms are used in different ways by the different models. Fortunately, it is possible to group various specific models of disability (such as those discussed in the previous chapter) into more general *types of approaches* to modeling disability, and then to draw some general analytical conclusions regarding the commitments that each type of approach makes regarding the meaning and import of the individual conceptual components. This generalization process is the principal task of chapter 2, and it serves as the basis for the argument, elaborated at the end of this chapter, that we need to move beyond the so-called "medical-vs.-social model impasse," in search of a deeper, more adequate theoretical/philosophical framework for understanding disability. This sets the stage for Chapter 3, which is devoted to the actual development of such a framework.

We begin with a reconsideration of the three central conceptual terms that appeared repeatedly throughout Chapter 1—namely, 'impairment,' 'disability,' and 'handicap'—with a view toward arriving at a clearer sense of the distinctions between them.

II. THREE CENTRAL TERMS: IMPAIRMENT, DISABILITY, HANDICAP

Having canvassed some of the most prominent models of disability, we are now in a position to begin pulling the various threads together and to draw some initial conclusions. We begin with the observation that three central terms, or close variations thereof, recur repeatedly in the disability literature—namely, 'impairment,' 'disability,' and 'handicap.' The "impairment-disability-handicap" formulation appears explicitly, of course, in the original WHO classification (ICIDH-1). The ICIDH-1, however, was theoretically grounded in Nagi's earlier model, which

employed an "impairment-functional limitation-disability" trichotomy. Indeed, though not identical, the "functional limitation" of the Nagi, IOM-1/IOM-2, and Verbrugge/Jette models roughly parallels the "disability" component of the ICIDH-1. Similarly, where Nagi, IOM-1/IOM-2, and Verbrugge/Jette speak of "disability," the ICIDH-1 speaks of "handicap." Finally, the social model is premised on a sharp "impairment-disability" distinction. Thus, given that all the prominent models of disability employ similar versions of the same terms—albeit, as we have seen, with sometimes very different meanings—the discussion here will, for purposes of expositional and analytical economy, be focused on the "impairment-disability-handicap" triad.

Before proceeding further, however, we first need to get a better grip on the relationships between these three terms. One way to approach this question is by way of a consideration of two key distinctions—namely, the impairment-disability distinction, on the one hand, and the disability-handicap distinction, on the other. As with most topics in the theoretical literature on disability, both of these distinctions have come in for serious scrutiny and challenge. A brief overview of the relevant disputes will be helpful for purposes of preparing the way for subsequent discussion in this work, especially part IV of this chapter, where we will return our attention to the ways in which the general approaches under consideration in this chapter tend to conceptualize each of these key terms.

A. Impairment Versus Disability

Disability rights activists and scholars frequently affirm this distinction, though it has more recently come in for questioning even in those quarters. The various formulations of the social model, in particular, typically rely on the distinction; indeed, as we saw in Chapter 1, the UPIAS and DPI definitions of disability turn entirely on an acceptance of the impairment/disability distinction. As Shakespeare (2006) points out, a strong impairment/disability distinction sets the "British social model" approach apart from the rest of the field of "social-contextual" approaches to disability. On this approach,

> [i]mpairment is defined in individual and biological terms. Disability is defined as a social creation. Disability is what makes impairment a problem. For social modellists, social

> barriers and social oppression constitute disability, and this is the area where research, analysis, and campaigning and change must occur (Shakespeare, 2006, p. 34).

Arguably, a good case can be made that a *sharp* "impairment/disability" distinction—or, more precisely, "the distinction between biological/individual impairment, and social/structural disability" (Shakespeare, 2006, p. 34)—is indeed more difficult to make out than it might at first appear. Shakespeare (2006, pp. 34-35) provides us with three key reasons for thinking this. First, impairment is a necessary (though not sufficient) condition for the experience of disability because "[i]f there is no link between impairment and disability, then disability becomes a much broader, vaguer term which describes any form of socially imposed restriction" (Shakespeare, 2006, pp. 34-35). That is to say, without some grounding in an identifiable (biophysiological) impairment—for example, being mobility-restricted due to quadriplegia—disability can potentially be defined so amorphously as to lose all conceptual and empirical clarity, as well as practical utility.[1]

Second, impairments are in many cases caused and/or exacerbated by social arrangements. In some instances, social practices such as war, malnutrition, poverty, and the like can directly cause impairments—as in, for example, the loss of a limb suffered in the explosion of a land mine used in war. In other cases, social and environmental barriers can dramatically worsen the impact of already-existing impairments, "both through action and omission" (Shakespeare, 2006, pp. 34-35). For example, "having to negotiate physical obstacles, or use badly designed seats or toilets or transport puts people at risk, and may cause pain or injury"; alternatively, "individuals might experience pain or other symptoms which could be alleviated by drugs or therapies, which are unavailable due to particular prescribing regulations, or to lack of income, or rationing" (Shakespeare, 2006, p. 35). In such cases,

> ...are the problems to be defined as socially imposed restriction of activity, or as impairment effects? If social provision was improved, the restriction might disappear, or at least be minimized. But if it wasn't for the impairment, there wouldn't be any restriction

[1] To be sure, A can be *distinct from* even though *grounded in* B. The main point here, however, is that disability and impairment are not easily *separable,* either conceptually or practically, contrary to what some social modellists seem to think.

in the first place. The problem arises out of the combination of impairment effects and social restrictions (Shakespeare, 2006, p. 35).

A third and final reason why the distinction between impairment and disability is not as clear-cut as might at first be thought, Shakespeare argues, is that the very judgment that a condition is an impairment is *itself* a "social judgment" (Shakespeare, 2006, pp. 34-35):

> The meaning of impairment is a cultural issue, related to values and attitudes of the wider society. The visibility and salience of impairment depends on the expectations and arrangements in a particular society: for example, dyslexia may not become a problem until society demands literacy of its citizens (Shakespeare, 2006, pp. 34-35).

Ultimately, Shakespeare concludes, these examples demonstrate that "impairment is always already social, while disability is almost always intertwined with impairment effects"; in the end, "[t]here can be no impairment without society, nor disability without impairment" (Shakespeare, 2006, pp. 34-35). Impairment and disability "interpenetrate" one another, such that both conceptually and practically speaking, "[i]t is difficult to determine where impairment ends and disability starts" (Shakespeare, 2006, p. 37).[2]

B. Disability Versus Handicap

In comparison to the impairment-disability contrast, the disability-handicap distinction has generated a greater degree of controversy and has thus received a proportionally greater amount of attention in the literature. Indeed, questions have been raised as to whether or not there even *is* a meaningful distinction to be drawn between 'disability' and 'handicap.' As an entrée into this dispute, let us consider the exchange between Lennart Nordenfelt and Stephen D. Edwards on this question (Edwards, 1997; Nordenfelt, 1997).

1. Edwards (1997) on the disability/handicap distinction

In his "Dismantling the Disability/Handicap Distinction," Stephen D. Edwards (1997) argues that the distinction is superfluous and should therefore be rejected. He advances this thesis by way of two sub-arguments, which, on his view, collectively support his conclusion

[2] These difficulties, Shakespeare goes on to suggest, need not be "debilitating" to the project of developing an adequate account of disability. Indeed, on his view, the "vagueness" inherent in these terms lends credence to the interactionist account of disability that he will go on to develop, according to which "disability is a complex interaction of biological, psychological, cultural, and socio-political factors which cannot be extricated except with imprecision" (Shakespeare, 2006, p. 38). (We will return to Shakespeare's "interactionist" account in Chapter 3.)

regarding the "superfluity" of the distinction. Edwards' first sub-argument focuses on the World Health Organization's (WHO) defense of the distinction it employs in its *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). In response, Edwards argues that the WHO's case for the distinction fails, and that the term's usage in *ICIDH* is superfluous. In his second sub-argument, Edwards considers a different attempt to establish the distinction—namely, the approach developed by Nordenfelt (1997)—and argues, in similar fashion, that Nordenfelt's case for the distinction fails. Given both of these failures, Edwards argues, the distinction itself ought to be rejected as superfluous.

a. Sub-argument #1

At the outset of his first sub-argument, Edwards observes that in the *ICIDH*, the WHO claims that 'handicap' is (1) value-laden and (2) "extrinsic" to the individual, whereas disability is *not* value-laden and is "intrinsic" to the individual in question. By contrast, Edwards argues that, in fact, 'disability' *is* value-laden and encompasses factors that are "extrinsic" to the individual. Since WHO's distinction between 'disability' and 'handicap' turns on these putative differences in value-ladenness, as well as extrinsic vs. intrinsic factors, Edwards concludes that the WHO distinction fails and is, in fact, superfluous.

In his reconstruction of the ICIDH's framework, Edwards identifies the three central features of its account of 'disability': first, disabilities result from (are caused by) impairments; second, they are "context-neutral," i.e., they are not "determined by the specific social context of the individual"; and finally, they are "intrinsic to persons," that is, they are not the result of factors external to the individual in question (Edwards, 1997, p. 591). Further, on the *ICIDH* account, 'disability' is considered to be a "non-evaluative" term (Edwards, 1997, p. 593). By contrast, 'handicap' is, according to the *ICIDH*, (a) the result of impairment *or* disability;[3] (b) an evaluative (and comparative) term, and (c) "extrinsic" in the sense of being caused by factors outside the individual in question. In response, Edwards argues—contrary to *ICIDH*—that 'disability' inevitably involves factors that are extrinsic to the individual. He arrives at this conclusion by way of the following line of reasoning. First, *dis*ability is understood against the broader backdrop of

[3] On this account, impairment is a necessary condition for both disability and handicap, but disability is not a necessary condition for handicap.

an understanding of *ability*. But, Edwards says, "analysis of the concept of ability strongly suggests that no account of ability can be given which avoids references to phenomena beyond the person" (Edwards, 1997, p. 597). An *ability* to do X requires the existence and satisfaction of certain conditions beyond (external to) the individual who has the ability—what Edwards terms "manifestation conditions." Thus, to borrow his examples, an individual could not be said to have the ability to read books if books did not exist, or the ability to swim were there no locations (at least possible locations) in which one could swim. This idea, Edwards says, can be extended to an analysis of disability, such that "[j]ust as it is not possible to ascribe to X an ability A independently of consideration of phenomena beyond X's body, it is not possible to ascribe to X a disability independently of consideration of such phenomena" (Edwards, 1997, p. 597). And, Edwards goes on to say, if this latter conclusion is valid, then "it follows that no adequate account of disability can be gleaned from conceptual resources which make no reference to phenomena beyond the body of the person" (Edwards, 1997, p. 597). Therefore, one set of "extrinsic presuppositions" (Edwards, 1997, p. 598) in terms of which disability must be understood is the set of "manifestation conditions" required for any given disability to exist.

A second set of "extrinsic presuppositions" for disability, Edwards contends, is what he terms "value conditions"—that is, those moral and other values that are assumed to exist in the society in which a given individual with a disability exists. Edwards notes, for example, that the WHO's account of disability in the ICIDH assumes a form of moral individualism, where the definition of "disability" requires that individuals be classified as "disabled" in terms of states/conditions in which they are not assisted by other persons—that is, *independence* is emphasized above other values (Edwards, 1997, p. 598).[4] Such an account preserves the notion that disability is "intrinsic" to the individual. But, Edwards observes, not all societies are committed to the value of moral individualism, and so disability will not be strictly intrinsic in those societies. If this is the case, then what counts as a disability in one society may not count as disability in another; consequently, disability inevitably presumes certain background "value conditions."

[4] Cf. also the Verbrugge/Jette (1994) model, which emphasizes the lack of assistance from others and/or equipment; see Ch. 1, pp. for further discussion.

Turning now to the notion of "handicap," Edwards develops a similar argument to the conclusion that the *ICIDH's* account of the term is faulty. According to the WHO, while 'disability' is transcultural—that is, not "tied to specific cultural contexts"—handicap *is* restricted to specific cultural contexts. But this apparent distinction between the two terms, Edwards counters, is valid only if one *presupposes* moral individualism across all cultures. If, on the other hand, a "non-individualistic value system" is possible—as Edwards has argued in this paper is the case—then 'disability' will turn out to be as context-specific (i.e., "tied to specific cultural contexts") as 'handicap,' and the putative distinction between the two terms (on the basis of whether or not they are "transcultural") dissolves.

Similarly, Edwards insists, the foregoing line of argument provides resources for questioning the other ground upon which WHO argues for a distinction between 'disability' and 'handicap'—namely, the claim that the former (disability) is caused (only) by "intrinsic" factors (i.e., impairments), whereas the latter (handicaps) are caused by both "intrinsic" and "extrinsic" factors. In contrast to this, Edwards argues,

> the above points suggest that, as with handicap, the causes of disability are two-fold: they are partly intrinsic (impairments) and partly extrinsic (social and environmental phenomena). So given that for the WHO it is extrinsic social values which lead to handicaps, in conjunction with impairments, and given that our discussion suggests that the same is true for disabilities, it seems plausible to claim that disability be conceived of as a disadvantage brought about by factors both internal and external to the person (Edwards, 1997, pp. 597-598).

But if this is the case, Edwards concludes, then the alleged distinction between the two terms—at least as cast by the WHO account—must fail.

b. Sub-argument #2

Having (in his view) dispensed with the WHO's argument for a distinction between disability and handicap, Edwards now turns to a consideration of Nordenfelt's (1997) attempt to defend the disability/handicap distinction in terms of a distinction between "basic" and "non-basic" (or "generated") actions. Nordenfelt agrees with Edwards that the disability/handicap distinction

cannot be drawn along the lines attempted by the WHO—i.e., in terms of value-ladenness versus value-neutrality, or in terms of intrinsic versus extrinsic factors. Nonetheless, Nordenfelt accepts and seeks to defend the disability/handicap distinction, in large measure because of what he sees as its practical necessity and pragmatic usefulness. To that end, Nordenfelt distinguishes between disability and handicap in terms of "basic" versus "generated actions"—where a "basic action" is one "which is not performed by the performance of some other action," and a "generated action" is one that *is* performed by the performance of one or more basic actions (Nordenfelt, 1997, p. 611). An example of the former would be 'raising one's arm'; an example of the latter would be 'waving to someone by raising one's arm.' Disability, in turn, is "a non-ability to perform a basic action, for instance a non-ability to lift one's arm; [and] a handicap is a non-ability to perform a generated action, for instance, a non-ability to perform one's work properly" (Nordenfelt, 1993, p. 23, quoted in Edwards, 1997, p. 598). "Nonabilities" is, for Nordenfelt, a technical term—referring to "the class of abilities which an individual lacks" (Edwards, 1997, p. 598)—and it can range not only over specific actions, but over ranges of actions as well (e.g. the generated action of "getting to work" may be performed in a variety of different ways—walking, taking the train, driving a car, etc.—thus, there is a range of actions that can satisfy the description "getting to work").

In response to Nordenfelt, Edwards argues that: (1) basic actions are insignificant in themselves—that is, they are relevant only in relation to generated actions; and (2) a non-ability to perform (a range of) basic actions is neither necessary nor sufficient for handicap. In support of the first claim, Edwards notes that even in straightforward descriptions of ordinary, everyday activities—e.g. going to work, catching a taxicab to the airport in order to take a plane to some other city, chatting over a cup of coffee, and so forth—we rarely speak of or refer to the basic acts of which those generated acts are comprised. Although one might move one's finger in a certain way in order to sign one's name on a document, we typically speak of *signing the document* rather than *moving one's finger,* except in those cases in which the moving of the finger is particularly noteworthy (e.g., in the case of an individual with a spinal cord injury). What this suggests, Edwards says, is that "the importance of basic actions derives from their relations to

generated actions. Basic actions are not interesting in their own right, but only in so far as they have an effect at the level of persons" (Edwards, 1997, p. 602). And this suggests, in turn, that "*disability* is only of theoretical significance due to its relations with" what Nordenfelt (along with WHO) terms "handicap" (in a sometimes confusing usage, Edwards employs the term 'Disabilities' for 'handicaps,' and contrasts that with 'disabilities') [Edwards, 1997, p. 602].[5]

In this context, Edwards also adduces a number of concrete examples in support of the second claim, namely, that a non-ability to perform (a range of) basic actions is neither necessary nor sufficient for handicap (what Edwards terms 'Disabilities'). To this end, Edwards first asks us to consider a number of generated actions to which he has drawn our attention earlier in his article—"traveling to work, conversing with a colleague, writing, making coffee, going shopping, etc." (Edwards, 1997, p. 602). Would a paraplegic be able to perform all these generated actions? On reflection, Edwards observes, a very plausible answer to this question would be in the affirmative. The paraplegic may very well be able to use a wheelchair and a car to get to work, and there is no good reason to suppose that the paraplegic could not perform all the other generated actions listed (perhaps, in some cases, with the aid of assistive devices or other technology). To be sure, the paraplegic might not be able to perform these generated actions in the *usual*, *standard* ways that most other people perform them; nevertheless, the paraplegic *is* able to perform *other, nonstandard* basic actions in order to perform the generated acts—and hence, she would not be *handicapped* with respect to those generated actions. Thus, Edwards concludes, *non-ability* to perform particular basic acts is not a *sufficient* condition for handicap (understood in Nordenfelt's sense, as a non-ability to perform generated actions due to the non-ability to perform one or more basic actions). This is because

> *the person may still be able to perform an extensive range of types of actions whether or not it is possible for the person to perform a particular range of basic actions.* So non-ability to perform a range of basic actions is not a sufficient condition of [handicap] (Edwards, 1997, p. 603, italics in original).

---

[5] It is worth noting, in passing, that his criticisms of Nordenfelt notwithstanding, Edwards still ends up with *two* distinct terms—'disabilities' and 'Disabilities'—just as does Nordenfelt ('disability', 'handicap'). Apparently, *some* distinction between different senses of "disability" is needed, even if one follows Edwards in collapsing the "handicap" category into the "Disabilities" category.

If "non-ability to perform a range of basic actions" is insufficient for handicap, might it at least be a *necessary* condition? Edwards also answers this question in the negative. As he points out, even if one *is* able to perform a particular range of basic actions deemed necessary for the performance of certain generated actions, one might still be unable to perform those generated actions due to other factors. Thus, for example, one cannot travel if there are no means of transportation available; one cannot study if there is no material (books, etc.) available to study. In other words, "[i]f the social context necessary to perform certain kinds of actions is not in place, then one cannot pursue those actions"—and this will be the case regardless of whether or not one is able to "undertake a relevant range of basic actions" (Edwards, 1997, p. 604). Hence, Edwards concludes, one can be handicapped without the presence of a disability (understood as a "non-ability to perform a range of basic actions"), in which case disability cannot be a necessary condition for handicap. In Edwards' terms,

> the following two conclusions can now be drawn: (a) It does not follow from the fact that a person *is not* able to perform a "full range" of basic acts that the person is hereby not able to perform the range of acts characteristic of persons. (b) It does not follow from the fact that a person *is* able to perform a "full range" of basic acts that the person is, thereby, able to perform the range of acts characteristic of persons (Edwards, 1997, p. 604).

Hence, Edwards concludes, Nordenfelt's attempt to defend the distinction between disability and handicap fails. This, combined with his previous argument against the WHO's formulation of the distinction, leads Edwards to conclude, further, that the disability-handicap distinction is "superfluous" and should be rejected in favor of a singular category—"Disabilities"—that encompasses what the WHO and Nordenfelt meant by both "disability" and "handicap." At the end of the day, for Edwards, "the theoretical category of 'disability', where this is construed as distinct from 'handicap', is an idle wheel" and ought to be abandoned (Edwards, 1997, p. 604).

2. Nordenfelt (1997) on the disability/handicap distinction

Nordenfelt (1997) responds to Edwards' critique by presenting five largely pragmatic arguments for "The Importance of a Disability/Handicap Distinction"—namely, arguments from:

(1) practical necessity; (2) cost-effectiveness; (3) clinical practice; (4) vital goals; and (5) "the universal presence of some basic action."

Before advancing these arguments, Nordenfelt identifies two central points of agreement between him and Edwards. First, they both agree (*pace* ICIDH) that 'disability' cannot be understood independently of the context (social, physical, etc.) in which it occurs, by virtue of the fact that abilities—and, hence, disabilities—are always relative to a "specific set of circumstances" (Nordenfelt, 1997, p. 609).[6] Second, they both agree that 'disability' is an inherently value-laden term, if for no other reason than the fact that "abilities" and "inabilities" are identified with reference to evaluative judgments concerning the relative importance of various actions. We do not, for example, label the inability to wiggle one's ears a "disability," because that action is "considered inessential for most survival roles or life goals in general"—that is, being able to wiggle one's ears is not generally considered *important*, in comparison to other activities (such as being able to raise one's arms) which are clearly important in light of our typical roles and goals. But, as Nordenfelt points out, "judgments concerning importance presuppose evaluations," and evaluations always occur within the specific context of a particular framework (e.g., that of Western civilization, to which the ICIDH is, according to Nordenfelt, beholden) [Nordenfelt, 1997, pp. 609-610].

Later on in his essay, Nordenfelt mentions yet another point of agreement between him and Edwards, namely, that there is indeed a sense in which "generated" actions are in fact more fundamental—that is, more important than—"basic" actions, as Edwards contends. When it comes to descriptions of actions, we do ordinarily describe them at the "generated" rather than "basic" level—e.g., "I went to the store," "I drank a cup of coffee with a co-worker," etc., as opposed to "I moved my arm in such-and-such manner." This, Nordenfelt acknowledges, is plainly obvious. Nevertheless, we *are* interested in basic actions, particularly when it comes to theoretical reconstruction; here, "[i]t is on the level of theoretical reconstruction that we present the basic actions first and the generated actions later" (Nordenfelt, 1996, pp. 615-616).

---

[6] As Nordenfelt puts it, "When I say that I am able to walk outside I mean that I can do so given that the ground is reasonably smooth, that there is no hurricane outside, that no one physically prevents me, etc. So even the simplest action requires a context" (Nordenfelt, 1997, p. 609).

Such "theoretical reconstruction," in turn, is desirable for a number of practical and pragmatic reasons—which reasons constitute Nordenfelt's five arguments in defense of a disability/handicap distinction. In nutshell form, those arguments are as follows:

(1) The argument from practical necessity

As a practical matter, there may in some cases be only a single basic action—or, perhaps, a narrow range of basic actions—that is the dominant means by which a particular, desired endstate can be achieved, and it may be the case that, given the way the world is arranged and works, we know of no suitable replacement for that basic action. To be sure, Nordenfelt admits, it is "rarely the case that the favored basic action is absolutely necessary for achieving the desired end." Nevertheless,

> [t]he action may however in practice be necessary, given the way the society works; or it may be the only way which can lead to the desired end in an expedient and efficient manner, given the way society works (Nordenfelt, 1997, p. 617).

Hence, Nordenfelt argues, the distinction between disability and handicap in terms of basic versus generated actions is, in at least some cases, practically necessary and therefore pragmatically useful.

(2) The argument from cost-effectiveness

Here, the idea is that, as a practical matter, if certain desired ends can only be achieved via expensive technological devices, then it may be impractical and/or infeasible to employ such technologies. In such cases, those who are unable to perform the basic bodily movements that would have been replaced by such assistive technologies, are *handicapped* with respect to the achievement of that desired endstate, and *disabled* with respect to the basic action in question. Thus, Nordenfelt says, distinguishing between disability and handicap in terms of basic versus generated action has the virtue of enhancing cost-effectiveness.[7] The basic point here is that while "it may be true that a particular end can be achieved through many means, i.e., with help of different basic actions," nevertheless it may be that one particular means to a given end turns out

[7] With respect to this claim, one might wonder whether it is the distinction *itself* that enhances "cost-effectiveness," or whether a better way of putting things is to say that the distinction helps to *explain* functional differences in terms of judgments about relative cost-effectiveness.

to be "much more inexpensive to the person him or herself or to the society." For example, according to Nordenfelt, "[i]t is of course much less costly to walk to the nearest shop than to take a car or use a motorized wheelchair." In such cases, "[t]he technological devices can from an economic point of view never be as attractive as the bodily movements that they replace" (Nordenfelt, 2009, p. 618).[8]

(3) The argument from clinical practice

In his third argument, Nordenfelt appeals to the specific purpose for which the ICIDH was developed in the first place—namely to "answer to the great need of rehabilitative personnel for intellectual tools in identifying and communicating about the various consequences of diseases" (Nordenfelt, 1997, p. 618). In this regard, Nordenfelt points out that the majority of health-care professionals in the rehabilitation field—whether they be physicians, physical therapists, or occupational therapists—address disabilities mostly at the level of "bodily movement." Consequently, these professionals "need a language for the efficient communication about disabilities on the bodily movement level" (Nordenfelt, 1997, p. 618). In particular, there is a need for language that will enable them to identify relevant categories of disability toward which therapy ought to be directed, and that will provide them with a means of describing "both progress and decay in terms which are standard both nationally and internationally" (Nordenfelt, 1997, pp. 618-619). Thus, Nordenfelt concludes, "there is a clinical need for a terminology and classification of entities on the basic action level, i.e. disabilities" (Nordenfelt, 1997, p. 619).

(4) The argument from the subject's vital goals

Fourth, a given subject may have as one of his or her "vital goals" the performance of a basic action itself. For example, it may be of importance to a given individual to be able *to walk* through the forest rather than being carried through or otherwise being assisted by adaptive technology (e.g., a wheelchair). That is to say, "*it may be included in a person's set of vital goals*

[8] In her (2003), Silvers responds to this sort of claim with a counterclaim of her own, to the effect that people in wheelchairs are (or at least may be), in fact, more "comfortable" than those standing in line at the post office. Of course, the principal difficulty with such claims and counterclaims alike is that they represent extremely subjective judgments that depend in large measure on the individuals involved; people are, after all, highly complex and differ in many ways, including their subjective perceptions of "comfort." More broadly, these sorts of discussions raise conceptual issues about what counts as a "cost," which costs "count," which costs are more important than others, and so forth. When assessing relative costs, are economic considerations the only relevant ones? And what renders a given technology "attractive" or "unattractive"? Conceivably, advances in so-called "virtual reality" technology (and the like) might someday render conventional judgments of attractiveness and unattractiveness anachronistic. As one might expect, adjudicating these various disputes definitively is beyond the scope of the present work.

that he or she performs certain actions on the basic action level" (Nordenfelt, 1997, p. 619, italics in original). On Nordenfelt's view, the disability/handicap distinction provides the conceptual resources needed to account for this phenomenon.

(5) The argument from the universal presence of some basic action

Finally, Nordenfelt argues, the distinction between basic and generated acts will always be of relevance, particularly in the context of rehabilitation, because there will always be *some* basic action that corresponds with every generated action. Thus, *whatever* an individual's vital goals might happen to be, there will always be some set of basic actions which must be performed in order to achieve a given vital goal. And, given that different disabilities affect different basic actions in different ways, the distinction between disability and handicap in terms of basic versus generated actions will continue to hold traction and be of practical utility (Nordenfelt, 1997, pp. 619-620).

In these five ways, Nordenfelt concludes, Edwards fails to recognize "the need for identifying abilities and disabilities, for many health-care purposes, on different levels of abstraction and complication" (Nordenfelt, 1997, p. 608). Moreover, Nordenfelt believes, his own distinction between disability and handicap in terms of action theory (basic versus generated actions) provides the requisite conceptual tools with which to make such identifications.

3. Summary and initial conclusions

To recap the ground we have covered here, Edwards (1997) and Nordenfelt (1997) are debating the question, "is the disability/handicap distinction meaningful?" According to Edwards, the distinction is "superfluous," an "idle wheel" because, on his view, the principal attempts to defend the distinction—that of the WHO and that of Nordenfelt, respectively—both fail, for different but related reasons. In the case of the WHO, Edwards argues, the alleged distinctions between disability and handicap in terms of (a) value-neutrality versus value-ladenness, and (b) intrinsic versus extrinsic factors fails to capture the overlap between the respective categories. By contrast, Nordenfelt's attempt to draw the distinction along the simplicity/complexity dimension, in terms of "basic" versus "generated" actions, fails because, on Edwards' view, it misplaces the locus of theoretical and practical interest—namely, in basic rather than generated actions—as a

consequence of failing to recognize that basic actions are of interest only in relation to generated actions. In response, Nordenfelt (1997) argues that the disability/handicap distinction is in fact meaningful and relevant, Edwards' criticisms notwithstanding. Nordenfelt seeks to demonstrate this by advancing five arguments in defense of the distinction—namely, the arguments from practical necessity, cost-effectiveness, clinical practice, subjects' vital goals, and the universal presence of some basic action.

What are we to make of this dispute? On the one hand, Edwards seems correct in his argument that "normativity" (my term, not his) runs all the way down—that is, the sharp sort of distinction between "intrinsic" and "extrinsic" factors appealed to in the WHO's defense of the ICIDH "disability/handicap" distinction seems implausible at best, particularly in light of the arguments and illustrative examples adduced by Edwards. It *does* seem to be the case that "disability," however it is understood, will inevitably require reference to "external" or "extrinsic" features such as the context (environmental, etc.), as well as evaluative judgments regarding abilities (etc.) that are *valued* in a given society or culture (or for human beings generally)—and that, therefore, "disability" is inherently value-laden, or normative. (We will have more to say about this last point as the work progresses.)

On the other hand, it would appear that Edwards is not as successful in undermining Nordenfelt's *larger* project. To be sure, Edwards has raised some important difficulties for the attempt to cash out a disability/handicap distinction in terms of action theory (basic vs. generated action). In particular, Edwards' argument that "disability" (in Nordenfelt's sense) is neither necessary nor sufficient for "handicap" (in Nordenfelt's sense) does seem compelling. That having been said, this would appear to succeed only in proving a claim about the *relationships between* "disability" and "handicap," not that the notions themselves are somehow incoherent.

Nordenfelt's own rejoinders to Edwards' arguments suggest one possible way of resolving this dispute. As Nordenfelt shows (particularly in his arguments from "practical necessity," "vital goals," and the "universal presence of some basic action"), his way of distinguishing between disability and handicap is of particular relevance to clinical and rehabilitation settings (which is Nordenfelt's primary concern anyway). So, one option might be

simply to say that Nordenfelt's conceptual schema (i.e. one that preserves an impairment-disability-handicap trichotomy) is applicable in clinical settings, but not universally for all purposes. For other purposes (e.g., philosophical analysis of the concept of disability, planning social policy, etc.), we may need to move more in Edwards' direction, and speak only of impairment and disability.

In other words, it may very well be—as has been suggested by a number of prominent disability scholars and activists in recent years (cf. Silvers, 2009; Shakespeare et al., 2006)—that no *single* approach to modeling disability will suffice for all purposes.[9] With this in mind, we will henceforth speak primarily of 'impairment' and 'disability', rather than of 'impairment', 'disability', and 'handicap'. The rationale for this move is several-fold. First, virtually all discussions and/or models of disability, recognize *at least* impairment and disability, whereas some distinguish further between impairment, disability, and handicap. Second, as our discussion above revealed, it can be difficult to distinguish sharply between 'disability' and 'handicap'—the distinction between the two terms is, at best, unclear. Moreover, there has been a tendency in the literature to move away from use of the 'handicap' term in any event, given sensitivities in the disability community regarding the negative connotations that the term frequently carries. For these reasons, in what follows we will speak of an "impairment-disability" dichotomy, rather than in terms of an "impairment-disability-handicap" trichotomy, unless otherwise noted. This will be sufficient for our purposes, since the deeper philosophical question is whether or not there is an objectively "real" aspect to the disability phenomenon (i.e. impairment), or whether the disability phenomenon is shot through entirely with socially constructed values (i.e. "impairment," as much as "disability," is a social construction to be understood nominalistically, as the unconstrained

[9] One might wonder whether this claim undermines the larger project in which this work is engaged—namely, advocating a "biopsychosocial model" or approach to disability. The worry here would be this: in claiming that a (modified) BPS approach is superior to others, on the one hand, while simultaneously suggesting that different models of (or approaches to) disability are appropriate for different purposes, it may appear that we are advancing claims that, if not mutually exclusive, at the very least do not sit well together. While it is possible that this is the case, a plausible response to this worry would be simply to suggest that the BPS approach is *generally* preferable, but not (necessarily) *universally* so.

social model theorists would have it). For purposes of getting at *that* distinction (and the questions surrounding it), we need not posit a *further* distinction between "disability" and "handicap."[10]

III. THREE GENERAL APPROACHES TO MODELING DISABILITY

We turn now to an overview of the major *types* of models[11] in terms of which disability has typically been characterized. Where relevant, brief critical analyses will be provided, in an effort to further elucidate some of the philosophical issues involved in developing a comprehensive analysis of the concept of disability. For the sake of convenience, we will follow the account of the models offered by Silvers (1998). Though Silvers is by no means a disinterested bystander—she is herself a strong advocate of the social model of disability—it will suffice for our purposes to retrace her steps in the present context, since our immediate objective

---

[10] As an illustration of what this sort of move might look like, consider the approach taken by Hans S. Reinders in his *The Future of the Disabled in Liberal Society: An Ethical Analysis* (2000, pp. 42-44ff.). In the context of a larger project in which he examines some of the ethical and practical ramifications of prenatal genetic testing (and increased genetic knowledge generally) for those with mental disabilities in the context of modern "liberal" societies, Reinders briefly considers the "disability/handicap" distinction, argues that the distinction as cashed out in the ICIDH is "weak" at best, and indicates that, for purposes of his larger project, he will simply (1) stipulate that "disability" and "handicap" are interchangeable and then (2) proceed accordingly to examine the implications of liberal political theory for those covered under that combined "disability/handicap" designation (Reinders, 2000, pp. 42-44).

In developing his argument that the ICIDH'S distinction between disability and handicap is weak, Reinders first recalls for the reader the ICIDH's conceptualization of those terms, where "...'impairment' is defined as malfunctions or malformations at the organic level, while 'disability' refers to limited capacities to perform certain activities on the personal level and 'handicap' refers to disadvantages due to such limitations on the social level" (Reinders, 2000, p. 42). The problem now becomes that the relevant "activities" in terms of which disability is defined have reference to the range of activities considered "normal" for human beings—that is, "[l]imitations that count as disabilities are deviations from what human beings are normally capable of performing" (Reinders, 2000, p. 42). But if that is the case, then "[t]he designation of a range of activities as 'normal' indicates that disabilities no less than handicaps are dependent on socio-cultural determinants" (Reinders, 2000, p. 42). As an example of this, Reinders points to a person who has only one leg, who then receives a well-designed, well-fitting prosthesis in place of the missing leg. With sufficient training, that individual will, Reinders says, be able to walk again but not able to engage in sports that require running. But being unable to participate in such athletic activities turns out to be a condition that is true of many others as well—for example, the elderly. By comparison with those groups of persons, then, we would be forced to say that the amputee is "disabled" but not "handicapped." But this sort of usage of these terms, Reinders goes on to say, is "counterintuitive inasmuch as the concepts of disability and handicap appear to be coextensive" (Reinders, 2000, pp. 42-43). Therefore, he concludes, "the distinction between disability and handicap as introduced by the ICIDH does not appear to be a very strong one" (Reinders, 2000, p. 43).

For this reason, Reinders says, he will use the terms 'disability' and 'handicap' interchangeably. This will suffice for his purposes because it turns out that what we are *really* interested in, when we speak of either "disability" or "handicap," is the (extent of) *social disadvantage* experienced by an individual who has a disease and/or impairment. A specific genetic disorder, for example, may or may not be expressed in such a way as to result in an experience of social disadvantage—and it is the experience of social disadvantage that is of particular relevance to Reinders' larger project. For that reason, he says,

> I will stipulate that 'disability' is synonymous with 'handicap' and that the more important task, at least for present purposes, is to distinguish the meaning of both these terms from the meaning of the term 'disease'. The difference is that where disease refers to physiological, psychological, or anatomical disfunction, disability or handicap refer to the social consequences of such disfunction (Reinders, 2000, p. 43).

Methodologically, our approach here will be similar to Reinders'. Since our larger purpose is (as we indicated above) to determine whether or not, and the extent to which, there is an objectively "real" aspect to the disability phenomenon (i.e. impairment), or whether the disability phenomenon is shot through entirely with socially constructed values, we will simply leave it an open question as to whether or not a *further* distinction is needed between 'disability' and 'handicap.'

[11] For economy of exposition, I will in this chapter speak interchangeably of "types of models," "types of approaches to modeling," "models of disability," and so forth. Unless otherwise noted, these various locutions should all be understood in light of this chapter's overall focus—namely, distinguishing among *general approaches* to modeling disability, rather than distinguishing among *specific instances* of such models.

is to provide a general overview of the models. Still, as noted above, we will pause occasionally to offer some brief critical analysis, in part to ensure that our presentation here is balanced.

Broadly speaking, three approaches to modeling disability have tended to dominate: the "moral model" approach, "medical model" approach, and "social model" approach, respectively. For purposes of this study, our focus will be primarily on the medical and social models, for reasons that will become clearer shortly. Although the moral model has a long historical pedigree, stretching from antiquity to contemporary times, the latter two dominate current discussions in the literature, and for this reason (among others) will be the primary focus of this work.

A. The "Moral Model" Approach

1. Overview

Historically, disability has frequently been conceptualized as stemming either from sin or some other moral defect in the individual with a disability or her relatives, or else from supernatural activity of some sort (e.g., divine blessing, demonic oppression, a curse, etc.). In a discussion of the origins and historical developments of this "moral model" of disability, Anita Silvers observes that while there tends to be a *general* cross-cultural, trans-temporal assumption that to be "anomalous" is to be "inferior," there are nevertheless "variations in the valuation of human anomalies" (Silvers, 1998, p. 57). Thus, for example, while multiple births are in some cultures considered to be "ominous" signs (the multiple siblings may compete for a single available soul), they are valued positively in other cultures. Along similar lines,

> [i]n New Guinea albinos are regarded as holy, while in Senegal they are considered to be ominous.... [T]he Bayaka reverence their blind but deride their deaf, the deaf members of an Amazonian tribe experience no social stigma because of the ability of the whole tribe to communicate in sign language. (Garland, 1995, p. 3, quoted in Silvers, 1998, p. 57)

Silvers also notes in this context the oft-cited historical case of Martha's Vineyard, in which a comparatively large deaf population were fully integrated into a society that regularly used sign language (Silvers, 1998, p. 57)—that is, the "anomaly" of deafness was simply incorporated into the broader cultural practices of the community.

Despite these variations in the evaluation of anomalous characteristics, Silvers says, it nevertheless remains the case historically that

> the disadvantage associated with having a disability typically has been attributed to the flaws, failings, or inferiorities of anomalous individuals or else to those with whom they are closely associated. From antiquity the traditional explanation for their disadvantage has supposed that there is some moral flaw, not necessarily theirs but perhaps that of their progenitors, for which failing they must suffer (Silvers, 1998, p. 57).[12]

Thus, for example, in Greek mythology both Hephaisto's deformed feet and Oedipus' blindness are attributed to moral flaws or failings. Moreover,

> [r]acial as well as individual deformity was interpreted as a punishment for what might loosely be described as the pagan equivalent to the doctrine of Original Sin.[13] Ailian, for instance, alleges that when the Lokrians ceased to submit maidens as tribute to the goddess Athena, their wives were afflicted with a disease that caused them to bear "crippled and monstrous children" (Garland, pp. 60-61, quoted in Silvers, 1998, pp. 57-58).

As further illustration of this typical pattern, Silvers points to the fact that the Songye of Zaire exhibit various attitudes toward, and different morally-charged understandings of, such diverse conditions as "monstrous births,"[14] dwarfism, albinism, the birth of twins, and the deformity of limbs resulting from polio (Silvers, 1998, p. 58, citing Devlieger, 1995, pp. 94-105).

The focus of this moral model, as Silvers explains it, is on moral *responsibility* for disability status. This is reflected, in various ways, in the writings of the ancient Greeks:

---

[12] One might question the characterization of the moral model here—specifically, its insistence that individuals with disability were seen as *necessarily* suffering for a moral flaw or failing (either their own or that of their progenitors). For example, in Christian contexts one could seek forgiveness (through confession, repentance, and penance) and, thereafter, it would no longer be the case that the individual *must* suffer. By way of rejoinder, though, it should be noted that on this account of the moral model, past moral failings are taken to be the explanation for why an individual is *now* suffering (in this case, from disability). This does not rule out the possibility of present or future forgiveness of sins; it merely purports to offer an explanatory account for why a given instance of disability came about in the first place.

[13] For a recent discussion of the historical development of this doctrine, from a cultural perspective, see Alan Jacobs, *Original Sin: A Cultural History* (New York: HarperOne, 2008). It is worth noting, in passing, that the quotation above uses "original sin" in the sense of an action that sets in motion an inescapable sequence of retribution/punishment. This is different than the Christian doctrine of "original sin," a point that Jacobs highlights in the introduction to his book.

[14] 'Monstrous birth' was for centuries a common nomenclature in Western medicine. It meant a sign or portent sent by the gods, or by God, to punish women for the sins of intercourse, usually with animals or during menstruation.

> [I]n the *Protagoras,* Plato remarks that others' helpful intervention is appropriate only if a disabling condition is self-induced. If nature or luck enfeeble somebody and thereby place him at a disadvantage, there is no point in interfering in the hope of initiating a change. Aristotle tells us that blindness, when due to factors beyond a person's control, properly evokes pity, but it is shameful when caused by condemnable conduct such as excessive drinking (Silvers, p. 58, citing Plato, *Protagoras* 323d and Aristotle, *Nicomachean Ethics* 3, 1114a, 25-28).

For the ancient Greeks, then, disability is "the due of flawed individuals" (Silvers, 1998, p. 58). The underlying notion here is that of *desert*: "disadvantage is the deserved consequence of impairment because impairment itself is likely to have been earned, if not by the individual who suffered it, then by some ancestor who failed to be sufficiently solicitous of his descendant's welfare" (Silvers, 1998, p. 58).[15]

Along with these sorts of attributions of moral *responsibility* for disability, the moral model has, on Silvers' account, tended to emphasize *compensation* of the individual with a disability. Thus, the ancient Greeks provided public support for their disabled war veterans and the incapacitated indigent. In the case of certain disabilities, the individual with a disability was considered to have been compensated by it in other, non-monetary ways—e.g., blindness was taken to have the power to "transfigure" the blind individual, by providing her with compensatory powers of perception (spiritual and otherwise) that far surpassed those of other persons.[16] These ancient themes are important, on Silvers' view, because they reveal that "from antiquity, the idea has been maintained that disability invites compensation" (Silvers, 1998, p. 58).

These sorts of accounts of disability—that is, explanations of disability in moral terms—are not mere relics of a long-distant past; indeed, they continue to be held in various contemporary settings. As but one example of this, sociologist Michael Oliver cites an anthropological study by Gwaltney (1970, cited in Oliver, 1990, pp. 16-17) of attitudes toward blindness exhibited by the residents of a Mexican village. Gwaltney found that in that context,

---

[15] For an extended philosophical discussion of the concept of "desert," see Sher, 1989.

[16] At the same time, impairment was also often "associated with lack of self-control and abandonment of other-regarding virtues"; in fact, the compensatory powers conferred by disability were often considered to be dangerous to others (cf., for example, Tiresias in *Oedipus Rex*). Silvers, 1998, p. 59, citing Garland, pp. 29, 34.

"filiarly induced blindness [was considered to be] the consequence of omnipotent, divine intervention" (Oliver, 1990, pp. 16-17). Rather than being viewed as "a tragedy that affected particular individuals," for which the individual was to be held morally responsible, blindness was instead seen as "part of the struggle to live in a harsh environment which could impose a number of disasters on the community, and hence blindness was a problem of the community and not for afflicted individuals" (Oliver, 1990, pp. 16-17).

Consider, too, the ways in which disability is viewed in various religious contexts throughout the world today (JAF, 2009, pp. 20-22).[17] In certain religious and social systems, persons with disabilities are routinely "shunned, viewed as cursed, treated as an object (of charity, shame, or dishonor), or assigned to the lowest class of society" (JAF, 2009, p. 21). For example, Hinduism views disability as being the result of "bad karma," and persons with disabilities are accordingly relegated to the lowest caste in the social system (JAF, 2009, p. 21). In Islamic "shame and honor" cultures, disability is viewed as being a person's fate (*inshallah*), and persons with disabilities are treated as objects of charity and/or disgrace (JAF, 2009, p. 21). In Buddhism, disability is assimilated to other forms of pain or suffering—which, ultimately, are considered to be illusions to be denied or ignored (JAF, 2009, p. 21). In religious cultures dominated by spiritism, disability is viewed as being the result of a curse—that is, "a calamity/disaster invoking a higher being (deity)"—and the disabled person is treated accordingly:

> In some African cultures, taboo[18] is tribal law. Breaking a taboo brings a curse, which can be pronounced by either a human being or a mythical deity. The object of the curse is a person or family, and as a result of the curse, something bad happens to the person or family upon whom the curse was placed. In this way of thinking, a disability happens to a person or family as a result of a curse. Believing that the disability is a result of the curse,

---

[17] The material in this paragraph is drawn from an international training curriculum published in 2009 by the Joni and Friends International Disability Center, henceforth referred to as JAF, 2009. The cited material in the JAF curriculum is, in turn, drawn largely from the following sources: Eareckson Tada & Jensen, 2006; Lausanne Committee for World Evangelization, 2004a; Ponten, 2004.

[18] A *taboo* is defined as:

> 1. A prohibition imposed by social (societal/tribal/religious) customs. 2. Prohibition against touching, saying, or doing something for fear of immediate harm from a supernatural force. 3. Something prohibited by a taboo (JAF, 2009, p. 22).

all of the people in the community accept that decision. As a result, the person lives marginalized and isolated from their community (JAF, 2009, pp. 21-22).

The practical upshot of this, for persons with disabilities, is that they are frequently the bearers of social stigma, as a result of which they are excluded from social participation:

> Disability in Africa and in other parts of the world is seen as a stigma—a mark of disgrace in the family, bringing bad luck, or a punishment for sin that the parents (or other relatives) have committed. As a result, disabled people are often excluded from education, employment, services, and social and community activities. They are virtually guaranteed to live out their lives as the poorest of the poor.
>
> The social stigma associated with disability results in marginalization, discrimination, and isolation, often leading to individuals with disabilities literally begging for survival. Alms are given to the disabled person as a means of obtaining spiritual grace and forgiveness for the non-disabled person (JAF, 2009, pp.21-22).

Historically, a moral model understanding of disease has been used to provide warrant for what we would now recognize as unjustified discriminatory practices, rationalized on the basis of invidious inferences of moral responsibility. In two infamous examples of this, runaway slaves were said to suffer from the disease of "drapetomania" and masturbation was said to be a disease (or, more precisely, a *cause* of various disease symptoms), underwriting in each case various forms of "treatment" (e.g., excision of the genitalia of female masturbators) that are now seen to be deeply unjust (see Cartwright, 1851/1981; Engelhardt, 1981; and Engelhardt, 1996, pp. 189-238 for more on these examples).

2. Brief critical analysis

By way of brief critical analysis of the foregoing accounts of the moral model approach, recall, first of all, the interpretive assertion (cited above) that for the villagers in Gwaltney's anthropological study, blindness was viewed as "a problem of the community and not for afflicted individuals" (Oliver, 1990, pp. 16-17). Now, we might argue here that this claim conflates, or at least obscures, the distinctions between two different (but related) sets of states of affairs—namely, the distinctions between (1) being a problem for the *individual* versus being a problem for

the *community*, and (2) being a *problem* for the individual versus the moral *responsibility* of the individual for being in that state. For starters, it may very well have been the case that the state of blindness was viewed as being embedded in a causal network—one involving a nexus of environmental hazards and "omnipotent, divine intervention"—to which the entire community was exposed, such that it was in that sense a "problem for the community." Still, it seems implausible to say that blindness, as such, was *not* a "problem" for those individuals who were "afflicted" with that trait. Among other things, the state of being blind would presumably have created a number of practical difficulties (e.g., problems in mobility) even if the individual was not held to be morally responsible for the state of blindness and was therefore not the subject of stigmatization or other forms of moral approbation. The salient point, for present purposes, is simply this: regardless of what one takes to be the causal factors underlying a given state of disability—moral, spiritual, genetic, physiological, anatomical, environmental, social, or whatever—the state of "being a problem for the community" and that of "being a problem for the individual" are by no means mutually exclusive.[19] And, moreover, it is perfectly consistent to hold that the state of being blind was (or is) a "problem for the individual," while nevertheless remaining agnostic regarding or absolving the individual of moral responsibility for being in that state. To the extent that a "moral model" approach to disability obscures or conflates these distinct states of affairs, to that extent it is rightly criticized.

As noted earlier, the moral model has a long historical pedigree, stretching from antiquity to contemporary times. However, for a number of reasons, this model does not receive much attention in the contemporary literature on disability. At least two factors seem to be at play here. First, there is a concern that the moral model stigmatizes those deemed to be disabled, particularly by virtue of placing moral responsibility for being disabled on the disabled person herself; in this way, it is said, the moral model effectively engages in "blaming the victim."[20] A

[19] Strictly speaking, Oliver's claim (as quoted above) is a *descriptive* claim about how a given condition was *perceived*—i.e., blindness was "seen as" or "viewed in" a certain way—rather than an ontological claim or statement about objective reality. The key point for present purposes, though, is simply to highlight the fact that the distinction between epistemology and ontology is always relevant in assessing whether or not certain states of affairs count as 'impairment' or 'disability.'

[20] In the Christian tradition, there was an available remedy under this moral model: through confession (and, perhaps, penance as well) one could be forgiven by God, and thereby also be made right with man. Thus, while the moral model accounted for one's *current* state of disability in terms of sin (etc.), in the Christian tradition this was not the final

second factor fueling the reluctance to explain disability in moral terms is that with the advent of modern medical technology and the accompanying increase in medical-scientific knowledge, previously unknown causal mechanisms (of a non-moral variety) can be more readily identified. For example, ulcers are now generally seen as being caused by viruses rather than, as had been previously thought, by stress. Given these "modern" causal explanations, moral explanations of disability are taken to be passé at best.

The underlying concern here seems to be the danger of making unwarranted inferences or attributions of responsibility, which have the effect of imposing unjustified and harmful stigmatization on individuals with disabilities. The modern response to this worry has been to abandon "moral" accounts of disability as such—though, of course, it is still recognized that people can engage in activities that contribute to *becoming* disabled (e.g., driving while intoxicated, diving into shallow water, etc.). The issue is how to characterize disability *itself;* the trend has been to move away from explaining disability *as such* in moral terms, and toward explaining it in either medical or social terms instead. Whether that move is *itself* warranted is, of course, a legitimate subject for debate. The general rationale for this move, however, seems to be a sort of precautionary principle: namely, avoiding even the possibility of unwarranted, invidious inferences or attributions of responsibility by avoiding "moral" explanation (of disability) altogether.[21]

To sum up, then, the moral model approach to disability can be faulted for obscuring or conflating two important sets of states of affairs—the distinctions between (1) being a problem for the individual versus being a problem for the community, and (2) being a problem for the individual versus the moral responsibility of the individual for being in that state, respectively. Moreover, worries in recent years about the dangers of making unwarranted inferences to or attributions of moral responsibility for being disabled, particularly in light of the potentially harmful effects that such invidious inferences can have on persons with disabilities, has led theorists in

---

word on the matter—forgiveness and redemption were available to the individual, thereby transforming the "blame" that previously attached to her. In short, in some cultures (past and present), the moral model is not wholly negative, only partly so, because in the end, the "stigma" of disability can be (morally/spiritually) transformed.

[21] In light of the previous note, we can now see what is at stake for contemporary social model theorists. Since the moral model has been abandoned, these theorists no longer have a way of transforming the "stigma" of disability—so that stigma now has to be prevented or eliminated, rather than (morally/spiritually) transformed. I owe this observation, and those in notes 12 and 20, above, to Laurence B. McCullough, in personal e-mail correspondence.

recent decades to eschew "moral model" approaches to disability altogether. Consequently, the medical and social model approaches dominate current discussions in the disability literature, and thus are the primary focus of this study.

B. The "Medical Model" Approach

1. Overview

More recently, the so-called "medical model" has dominated the discussion of disability and related issues. On standard understandings of the model, the medical model identifies the *causal locus* of disability as being, in some sense, "in" the individual; the individual is "disabled" by some feature—a "defect" (anatomical, physiological, etc.) or "loss" (amputations, etc.)—of her body. As Silvers explains it, since on the medical model disability is caused by "physiological or mental deficit," the model therefore "...fixes on reducing the numbers of people with disability by preventative or curative medical technology" (Silvers, 1998, p. 59). On Silvers' account, the medical model carries over from the moral model the notion of an "assignment of responsibility" for disability status, the difference being that where deficits were previously attributed to moral flaws or failings, they are now often attributed to such causal factors as "inadequate health practices" or "bad genes" (the latter retaining tinges of moral evaluation characteristic of the moral model) (Silvers, 1998, p, 59).[22] On the one hand, Silvers suggests, the medical model permits a distinction between "diagnosis" (in medical terms) of and "blame" (in moral terms) for disability status—a distinction which, she believes, is salutary (Silvers, 1998, p. 60). On the other hand, she goes on to say, traces of the moral model still bias the medical model, for

> given our conviction that science and technology can always meet the challenge posed by a threat to human life and health, people with disabilities—especially those who are chronically ill or dying—come to represent the failure of biomedicine's mastery over the human body.... [F]ailures must be explained away, and their embodiments hidden. One all too familiar way of doing both of these things is to attribute the failure to the victim and

[22] One could argue here that this is not quite right. On a strictly medical understanding of things, congenital disability is simply the result of errors of reproduction. Disability that results from accidental injury is simply a random occurrence. Disability resulting from non-accidental trauma is either caused by others or self-caused. Only in the latter case—that is, disability resulting from non-accidental trauma that is self-caused—does the medical model hold the individual responsible. Even then, the primary focus of the medical model will be on such things as psychiatric/psychological intervention as a part of the treatment plan, with a view toward ensuring that that responsibility itself does not become an impediment to effective management of and/or adjustment to the disability.

to blame, fear, and eventually physically isolate the victim... (Bickenbach, 1993, p. 82, quoted in Silvers, 1998, p. 60).

2. Brief critical analysis

By way of critical analysis of the foregoing material, two points are worth highlighting regarding Silvers' account of the medical model. First, when Silvers claims that *because* the medical model identifies "physiological[23] or mental deficit" as the cause of disability, the model *therefore* "...fixes on reducing the numbers of people with disability by preventative or curative medical technology" (Silvers, 1998, p. 59), this may very well be an example of the sort of conflation of causal explanations and social justice claims to which this study seeks to draw attention. At the very least, this seems to be a blurring of the distinction between causal explanations and prescriptive imperatives. For even if disability is *caused by* "physiological or mental deficit," there may in fact be different ways to *respond to* disability—which modes of response may or may not include an emphasis on "preventative or curative medical technology." There are, for example, conditions that cannot be prevented or cured *medically*—but the medical model may still have much to say about how the condition can be ameliorated, and this may very well include changes to the social or physical environment. It seems, then, that Silvers may be mischaracterizing the medical model—as a *causal explanation* (answering the "Why?" question about disability), the medical model leaves open the answers to questions having to do with how we ought to *respond* to disability. That is to say, the medical model offers a *medical-scientific explanation*, not a *moral normative explanation* or *prescription*. To conflate the two is, quite simply, to mischaracterize the medical model—and, perhaps, to mask its potential advantages (e.g., the liberation of diagnosis and treatment from the more invidious aspects of the moral model, by virtue of offering a reductive explanatory account in terms of underlying anatomical/physiological processes and the like, rather than appealing to possibly questionable moral values or assumptions).[24]

---

[23] It is worth noting that the medical model also recognizes anatomical deficits, which are of significance independent of any physiologic considerations.

[24] Indeed, as noted in the previous section, the moral model of disease, and therefore of disability, was rejected in medicine long ago; as suggested here, there are advantages associated with the biological/biomedical model, whatever else we might say about its disadvantages. I am grateful to Laurence B. McCullough for this observation.

Second, when Silvers says that the medical model carries over from the moral model the notion of an "assignment of responsibility" for disability status, she is surely correct. She goes on, however, to fault the medical model for being biased by this aspect of the moral model, and in doing so she implies that her preferred social model is *not* "biased" in this way. Yet, this seems patently false—at least if the claim is that the social model does not assign "responsibility" for disability status. For the social model clearly *does* assign causal responsibility for disability—on social structures and practices. So, it seems that no matter which model of disability we adopt, we cannot escape the question of responsibility for disability status: *all* models of disability will make causal claims regarding the source, or origin, of disability (even if their *primary* focus is on the "What?" rather than the "Why?" question), and thereby engage in an "assignment of responsibility."

The preceding paragraphs essentially amount to criticisms of certain *critiques* of the medical model. It is important to reemphasize in this context, however, that the medical model (or "medical paradigm," as Reinders [2000] terms it) has itself come in for much criticism in the literature. Specifically, the model has been criticized for casting disability exclusively in medical terms, as being (nothing but) an individual "defect" that "renders the existence of disabled people intrinsically problematic" and, therefore, "turns to 'prevention' as the obvious solution to the problem" (Reinders, 2000, p. x). The problem with this approach, these critics say, is that

> [i]n conceiving disability primarily from a medical perspective, people tend to ignore its social and political dimensions. Persons with disabilities are not simply the victims of nature, but they are also often victims of a lack of opportunities in life. In ignoring the wider social and economic dimensions, the medical perspective fails to do justice to the daily experiences of people and their families. The question of whether a genetic disorder causes a disability depends as much on how our society responds as it does on biological conditions (Reinders, 2000, p. 3).

Instead, critics such as Reinders and others suggest, we ought to move away from a medical paradigm toward a "normalization" paradigm, one which emphasizes "potential" rather than

"defect" (Reinders, 2000, p. 2). This theme is picked up by advocates of the social model of disability, to which we now turn.

C. The "Social Model" Approach

1. Overview

Disability rights advocates have in recent years promoted what has come to be called the "social model" of disability, according to which the causal locus of disability is to be found in social structures and practices that have the effect of excluding—and thereby disabling—those whose physiological or cognitive constitutions render them "different" than the majority population (Silvers, 1998, 2009).[25]

As Silvers reconstructs it, the medical model assumes that the built/arranged environment is fixed and invariable;[26] consequently, disabilities are "defects of natural assets rather than of social assets." But these assumptions, Silvers argues, are questionable. To see this, she invites us to consider the question, what ties disablement "so tightly to disadvantage"? The answer to this question, she says, will shed light on whether "disablement is primarily a natural or social phenomenon" (Silvers, 1998, p. 74). Silvers goes on to argue that in many cases, the functional deficits customarily associated with disability "are neither more nor less than an alterable cultural artifact" (Silvers, p. 75). This is, in a nutshell, the conceptual heart of Silvers' social model approach, according to which one can always ask, with respect to any "handicapping condition," whether it is primarily a "state of a minority of people," on the one hand, or a "state of society," on the other. To the extent that a handicapping condition turns out to be a state of society rather than the individual, Silvers contends, the individual will enjoy a right to the alleviation or amelioration of that condition (Silvers, 1998, p. 75).

This approach is reflected in the landmark Americans with Disabilities Act (1990), which according to Silvers, "is thoroughly grounded in the belief that disability is socially constructed" and represents a fusion of philosophical strands of thought from Hegel, Marx, and Foucault with

---

[25] For an important formulation of the social model, one that is frequently cited in the literature as a seminal work, see Oliver, 1990.

[26] Here again, this seems incorrect. The medical model can consistently situate the causal locus of disease or disability "in the individual" (in the senses elucidated in the above discussion) while also acknowledging the role of the built/arranged environment both in bringing about disease/disability, as well as in the management of disease/disability. Indeed, changes to one's built/arranged environment are frequently included as elements in a comprehensive program of rehabilitation.

the "classical liberalism of the American civil rights movement" (Silvers, 1998, p. 75).[27] On the philosophical view embodied in the ADA, "the isolation of people with disabilities" is the result of a complex interplay between the person with a disability, "stigmatizing social values," and "debilitating social arrangements."[28] Indeed, the rationale provided in the preamble to the legislation states explicitly that

> [h]istorically, society has tended to isolate and segregate individuals with disabilities.... [I]ndividuals with disabilities are a discrete and insular minority who have been... subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society... resulting from... assumptions not truly indicative of the... ability of such individuals to participate in, and contribute to society (Public Law 101-336, Americans with Disabilities Act of 1990, Section 2 (7), quoted in Silvers, 1998, p. 76).

In what amounts to an argument for preferring a social model approach to disability over against a medical model approach, Silvers offers three reasons for resisting an attempt to characterize disability in strictly "biological" terms. First, the relationship between biology and disability is "indeterminate" at best. Since "correlations between medically designated pathologies and limitations in competence are by no means reliable or firm" (Silvers, 2009, p. 25, citing Stone, 1984, pp. 116-117, 128), biological anomaly itself is a poor predictor of disability. Hence, one cannot simply equate "biological anomaly" with "disability."

Second, environmental factors affect functional limitation and subsequent achievement, as the Windows-DOS controversy amply illustrates. This controversy was occasioned by the fact that the Microsoft Corporation initially sought to keep the source programming for its Windows-

---

[27] Legally, the ADA can be seen as a combination of the rehabilitation and civil rights tradition, thus combining elements of both a "medical model' and "social model" approach to the "problem" of disability. See Illingworth and Parmet (2000) for further discussion.

[28] Silvers (1998, p. 76) interprets this as a rejection of the view that disability is a "natural kind." For a discussion of the concept of natural kinds, and its relation to disability, see Sulmasy (2009). As we noted in the introduction to this work, Tom Shakespeare (2006) also argues for a "relational" account of disability, according to which disability, "results from the interplay of individual and contextual factors," and people thus are "disabled by society *and* by their bodies" (Shakespeare, 2006, p. 2). Of course, even if one embraces such a "relational" account of disability, one will still need to distinguish between different senses of "being disabled"—and, in particular, between different senses of "being disabled by society." Consider, for example, the difference between being "kneecapped" by the mob versus being "disabled" by the failure of society to provide a motorized wheelchair for a quadriplegic. Arguably, both of these might count as having been "disabled by society," but just as clearly one sense seems to be literal (being kneecapped by the mob) while the other seems a metaphorical, non-literal sense. The significance of this is that it is not sufficient merely to say "X is disabled by society"—one must spell out precisely what one means by that locution.

based operating system and software confidential, citing competitive concerns. Consequently, makers of voice-recognition and other software that enabled deaf persons to use computers were unable to modify their software to run on Windows-based operating systems—thereby limiting the functional capacity of deaf persons in work and other related contexts. The dispute over this issue has recently been resolved, with Microsoft allowing access to its source code.[29]

Third, medical conditions underdetermine functional limitations. For example, people with the same degree of "prelingual" hearing loss can differ dramatically in their capacities to understand and make themselves understood, whether through lip-reading or speaking. Similarly, individuals with identical neural or muscular impairments can exhibit significantly different abilities to perform such actions as grasping, lifting, standing, and walking. Some persons with dyslexia succeed in certain "print-intensive occupations," whereas other individuals with dyslexia fail in those same occupations. The implication that should be inferred from these and other similar examples is, according to Silvers, that "the limitations of or constraints on acting freely that disability is presumed to impose call for more expansive or more nuanced explanation than medical diagnoses of biological conditions usually provide" (Silvers, 2009, p. 26). Ultimately, Silvers concludes, "the explanatory power of the biological model is confounded by a multitude of cases in which the markedly different levels of achievement (and different degrees of suffering, as well) of individuals with identical biological conditions appear attributable to differences in how the individuals are socially situated," rather than to their biological "anomalies" (Silvers, 2009, p. 26).

One of the reasons many disabled scholars and activists have embraced the social model, Silvers suggests, is that the social model explanation of disability yields/has yielded (positive) *political* results for persons with disabilities. Ultimately, the social model explains the "why" question in political terms, and appears to have satisfying results from the perspective of persons with disabilities. Importantly, however, she goes on to argue, the decision to alter the individual versus the environment is one that is both practical and value-laden (Silvers, 2009, p. 30).

---

[29] For more on this issue and recent developments, cf. Silvers, 1998, with Silvers, 2009.

If the social model provides an answer to the "Why?" question, does it also seek to answer the "What?" question? In this regard, Silvers says, the social model advances a "neutral" conception of disability (cf. Silvers, 2003), according to which "anomalies" are nothing more than "neutral human variation" which can be dealt with by means of identifying "alternative modes of functioning." Thus, the social model's strategy amounts to one of "distancing disability from dysfunction" (Silvers, 2009, p. 31). In response to the challenge that this amounts to a form of "denial," Silvers answers that it does *not* constitute denial, because (1) being "less preferable" (as is the case with dysfunction—i.e., dysfunction is "less preferable" to function) is not identical with being "inherently bad," and because (2) "disability" is, ultimately, merely a "natural state" of some people.[30]

2. Brief critical analysis

a. Analysis of Silvers' account

By way of brief critical analysis, we can raise four principal issues with Silvers' account as described above. First, why think that the medical model *does* assume "that the built/arranged environment is fixed and invariable"? Arguably, this constitutes a mixing of domains of explanation: the medical model focuses on underlying anatomic/physiological structures and processes, not the "built/arranged environment." One need not make *any* assumption, one way or another, about the built/arranged environment. Indeed, on George L. Engel's biopsychosocial model (to be discussed at length in the next chapter), which Engel intended as an *extension* rather than a straightforward rejection or replacement of the medical model, the claim that the built or arranged environment is "fixed and invariable" is simply false—in which case, the medical model *need not* be taken to have such an assumption (regarding the invariability of the built/arranged environment) embedded in it.

Second, why think that in many cases the functional deficits customarily associated with disability "are neither more nor less than an alterable cultural artifact"? As possible counterexamples to this claim, consider such conditions as blindness and profound mental

[30] Silvers does not distinguish in her discussion between what we are here calling the "constrained" and "unconstrained" versions of the social model. Her way of putting it here is, of course, suggestive of the *unconstrained* rather than constrained version.

retardation. Is it really plausible in such cases to claim that the functional deficits associated with them are *nothing more or less than* "alterable cultural artifact[s]"? In fairness, it should be acknowledged that the claim in question is not that *all* functional deficits are nothing more or less than alterable cultural artifacts, only that this is true in *many* cases. Still, the burden of proof would seem, at least *prima facie*, to be on the one who would seek to establish the plausibility of such a sweeping claim.

With respect to the framing of the Americans with Disabilities Act (1990) in terms of civil rights legislation prohibiting racial discrimination, it can be argued that, in fact, there is a significant *disanalogy* between race and disability—namely, the existence of an underlying biological substrate in one case (disability), where such an underlying biological substrate is, arguably, absent in the second (race). In using the civil rights laws as a template for framing the ADA, the operative assumption seems to be that disability is relevantly analogous to race, which (arguably) is socially constructed and has no firm biological basis. However, one might argue to the contrary, this assumed analogy (between disability and race) fails to appreciate that disability, unlike race, has a clear biological component that can be reliably diagnosed, bio-causally explained, and ameliorated if not eliminated altogether.[31] (We will return to this topic momentarily.)

Finally, we might point out that Silvers' way of framing the discussion—i.e., in terms of a choice between whether "disablement is *primarily* a natural or social phenomenon" (italics added; see Silvers, 1998, p. 74, quoted above)—should alert us (again) to the fact that the social model, *as much as the moral and medical models*, is indeed concerned with "assigning responsibility" for disability status.

b. On the analogy between race, sex, and disability

As we saw above, an explicit analogy is often drawn between the experience of disabled persons, on the one hand, and that of women, members of minority ethnic communities, and members of the lesbian and gay communities. The central claim is that just as members of those other groups are discriminated against and oppressed on the basis of morally irrelevant

[31] I am grateful to Laurence B. McCullough for alerting me to this distinction and for providing some of the language used here.

features—what amount to "mere" (biological) differences—so, too, disabled persons are invidiously discriminated against and oppressed on the basis of mere biophysical differences. It is worth asking, however, whether this analogy really goes through. On the one hand, as Shakespeare (2006) observes, "[a]s social movements, women's liberation, gay rights, disability rights and anti-racism are similar in many ways. Each involves identity politics, each challenges the biologisation of difference, [and] each has involved an alliance of academia and activism" (Shakespeare, 2006, p. 41). On the other hand, Shakespeare goes on to argue, the "oppression" experienced by disabled persons is "different from, and in many ways more complex than" that experienced by members of those other groups (Shakespeare, 2006, p. 41). For one thing, while it is undeniably true that women and men are both physiologically and psychologically different from one another, it is no longer plausible to claim that women are "made less capable by their biology" as such (Shakespeare, 2006, p. 41). Similarly, Shakespeare says, "only racists would see the biological differences between ethnic communities as the explanation for their social differences. Nor is it clear why being lesbian or gay would put any individual at a disadvantage, in the absence of prejudice and discrimination" (Shakespeare, 2006, p. 41). By contrast, Shakespeare contends, "...even in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult, not neutral" (Shakespeare, 2006, pp. 40-41). Indeed,

> disabled people often experience major disadvantages as a result of their genetic endowment, whereas members of other historically oppressed communities experience either minimal or non-existent biological disadvantages. For a few disabled people, their genetic condition is the most salient aspect of their entire existence (Shakespeare, 2006, pp. 41-42).

Moreover, unlike those in the "comparator groups," a relatively small number of the limitations or restrictions experienced by persons with impairments can be traced to factors that are entirely "social" in origin; instead, more often than not the experience of persons with disabilities can be characterized as involving a combination of both "the intrinsic limitation of impairment" and "externally imposed social discrimination" (Shakespeare, 2006, p. 40-41). Given these

considerations, then, it would seem prudent, at the very least, to avoid "simplistic" comparisons between disabled persons and "other historically oppressed groups," so as to avoid drawing unwarranted conclusions (Shakespeare, 2006, pp. 41-42).

c. General critiques of the social model

More generally, the social model has been criticized as being prone to difficulties at three levels—(1) conceptual, (2) application, and (3) implementation, respectively. At the conceptual level, the model has been criticized for neglecting the relevance and significance of impairment and its impact on personal experience. At the level of application, it has been criticized for being "difficult to apply to groups of disabled people other than the people with physical impairments by whom it was devised" (Shakespeare, et al., 2006, p. 1104).[32] And at both the levels of application and implementation, it has been pointed out that "applying and implementing social approaches is difficult in practice, and sometimes impossible" (Shakespeare et al., 2006, p. 1104).

There are, according to Shakespeare (2006), three problems in particular with the notion of achieving a "barrier free utopia"—problems having to do with (1) "nature," (2) "incompatibility," and (3) "practicality," respectively. First, the claim that "people are disabled by society, not by their bodies" works well with respect to urban and highly-populated areas, where "human-created obstacles to participation in society" are rampant. Once one moves out of the city and into rural and less highly-populated areas, however, the explanatory power of the social model becomes less compelling. Particularly problematic is the limiting effects of inhospitable natural environments that cannot plausibly be attributed to social arrangements; as Shakespeare puts it, "[i]t is hard to blame the natural environment on social arrangements" (Shakespeare, 2006, p. 45). Second, there are potentially intractable problems related to incompatibility:

> Implicit in the notion of a barrier-free world is the idea that Universal Design[33] can liberate all. Yet, while in each case a solution to an access barrier can be found, taken as a totality it may be impossible to create one environment which is accessible for all

---

[32] Cf. the UPIAS formulation of the social model (see Ch. 1 of this work), which defines disability in terms of *physical* impairments.

[33] Universal Design has been defined as "[t]he design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Centre for Universal Design, 1997, quoted in Shakespeare, 2006, p. 44).

potential users. The principles of Universal Design are unarguable when taken separately, but may create conflict when aggregated (Shakespeare, 2006, p. 46).

Finally, there are issues of practicality that may render the achievement of a barrier-free utopia unlikely at best. For example, many buildings and other facilities were constructed "in an era when the participation of disabled people was never considered" (Shakespeare, 2006, p. 47). Requiring massive retrofitting or other modifications to such buildings and facilities to render them "accessible" may impose costs that are so burdensome as to render such mandates simply unfeasible. Indeed, as Shakespeare points out, removing barriers entails a "rebuilding" of society—which, in turn, inevitably leads to trade-offs as different considerations (e.g. ease of access to facilities versus costs associated with modifications) are weighed in the balance.[34]

IV. COMPARATIVE ASSESSMENT OF THE GENERAL APPROACHES

We turn now to a comparative assessment of the relative strengths and weaknesses of the general approaches to modeling disability. In Chapter 1 we identified how each of the *specific* models of disability conceptualize that term; we begin this part of Chapter 2 by engaging in that same sort of analysis vis-à-vis the *general* approaches.

A. Conceptualizations of Disability in the General Approaches

As we have seen, the disputes over the nature of disability can be understood as, *inter alia*, a debate over how best to conceptualize disability. Importantly, models create a sort of "picture" of what it is they are modeling; in the case of disability, models of disability can be said

---

[34] Taken together, these three considerations place pressure, at a theoretical level, on the coherence of the social model approach to disability. In this regard, Shakespeare cites Neil Levy's (2002, p. 139) argument that there are two necessary conditions for a "social causation model of disability" to be successful: "first, it must be possible to alter social arrangements so as to remove disadvantage and second, there must be no compelling reason why social arrangements could not be altered" (Shakespeare, 2006, p. 49). But, as the problems of practicality mentioned above suggest, "[r]esource constraints are sometimes a compelling reason preventing the removal of barriers" (Shakespeare, 2006, p. 49). Moreover, as the problems of nature and incompatibility suggest, there can be situations in which "[t]he specifics of impairment... create disadvantages which no inclusive social arrangements can mitigate. In these situations provision of alternative ways of accessing facilities can often be both appropriate and acceptable" (Shakespeare, 2006, p. 49). But then neither of the necessary conditions for the success of the social model is satisfied; thus, "on a theoretical level, the barrier-removal solution to disability does not fully succeed, and this failure undermines the tenets of the social model."

Rather than bemoaning this failure on the part of the social model, Shakespeare once again points to the fact that the social model—and, specifically, the goal of barrier removal—was, all along, intended to be a *means* to an end rather than an end in itself: "The disability rights movement has always worked for inclusive provision and a barrier-free world. But barrier removal is not an ends in itself. It is a means to an end. The aim of barrier removal is to facilitate the participation and improve the quality of life of people with impairment" (Shakespeare, 2006, p. 50). Given that aim, then, it will sometimes be the case that "separate or alternative provision for disabled people may be a more appropriate way of enabling them to achieve their ends and goals" (Shakespeare, 2006, p. 50). In other words, disability advocates ought not to lose sight of the proverbial "forest"—facilitating social participation and enhancing the quality of life of persons with disabilities—for the "trees" of barrier removal as such. To the extent that the social model encourages us to lose sight of that real goal, to that extent it is (on Shakespeare's view) rightly criticized.

to paint a general portrait of what disability "is." Depending on the model of disability in question, the way in which disability is conceptualized will differ. Based on our survey of some representative specific models of disability (Ch. 1) and the three general approaches to modeling disability (Ch. 2), we can identify four leading candidates[35] for *general conceptualizations* of disability: (a) disability as defect/limitation; (b) disability as personal tragedy; (c) disability as a neutral "form of variation"; and (d) disability as (a form of) culture. The first two are (rightly or wrongly) typically taken to be associated with the medical model. In response to what they take to be the shortcomings of such a conceptualization of disability, many social model theorists have proposed the latter two as alternative ways of conceptualizing disability.

For the moral model approach the "problem" of disability is located "in" the individual—that is, in a moral flaw or failing of the individual (and/or her ancestors). In this sense, then, the moral model approach can be understood as positing that "disability" is an *intrinsic* predication regarding the individual. Moreover, given that disability is seen as being caused by a moral flaw or failing on the part of the individual or her ancestors, it is reasonable to infer from this that the moral model approach conceptualizes disability in terms of "defect." Further, "moral model" understandings of disability frequently conceive of disability in tragic terms, as a "personal tragedy" that has befallen the individual (and that can, in many instances, have disastrous consequences for the community as well). In sum, then, we can say that the "moral model" approach to modeling disability typically conceptualizes it in terms of an intrinsic feature of the individual, one arising from a moral defect and experienced as a tragedy for the individual and/or her community.

For the medical model, as we have seen, the "problem" of disability—its causal source (or locus), and typically the focus of intervention as well—is to be located "in" the individual, that is, in a biological, anatomical, or physiological "defect" of the individual. Moreover, in medical model accounts of disability, the language of "tragedy" tends to dominate. Indeed, it has been observed repeatedly in the literature that medical professionals (and non-disabled persons generally) have a marked tendency to view disability and disability-related sequelae in a much

[35] There may be other "candidates" out there; this is not intended to be an exhaustive list.

more negative light than those who "suffer" from or are "afflicted" with such conditions.[36] Therefore, it is not unreasonable to think that a "medical model" approach, while not necessarily *entailing* a "tragic" view of disability, nonetheless tends in that direction. (Whether this way of viewing disability is either accurate or salutary is, of course, a separate question, one to which we will return shortly.) Given the foregoing, we can say that a medical model approach to disability tends to conceptualize disability as being an "intrinsic" feature of the individual in question—that is, 'disability' involves *intrinsic* predication—a feature which is best understood as being a biological/anatomical/physiological "defect" and/or as having "tragic" experiential implications for the person who has that trait.

Finally, we have seen that the social model approach sees the "problem" of disability as residing in, or being constituted by, social oppression, discrimination, and neglect rather than in features intrinsic to the individual. Thus, the social model can be said to characterize "disability" as involving *extrinsic* rather than *intrinsic* predications. Further, we also saw that social model advocates frequently advance arguments that disability in fact amounts to nothing more than a neutral "form of variation" and/or a "form of culture." Combining these two sets of observations, then, we can say that the "social model" approach tends to conceptualize disability as involving *extrinsic* rather than intrinsic predications, and as painting a "picture" of disability as a neutral variation and/or form of culture.

As we will demonstrate momentarily, the fundamental problem with these accounts is that they each miss something important about the reality of disability that ought to be captured by any adequate account. Conceiving of disability exclusively in terms of either a defect in the individual or as a personal tragedy grossly underestimates the significant role that social attitudes and practices, as well as environmental factors, can play in the production, maintenance, and exacerbation of disability. On the other hand, casting disability as "nothing but" a neutral variation and/or as just another "form of culture" seriously neglects the significant role that impairments as such can play in the lived experience of those who have them. The obvious lesson to be drawn

[36] See, e.g., Cameron, Titus, Kostin, & Kostin, 1973; Woodrich & Patterson, 1983; Stensman, 1994; Cushman & Dijkers, 1990; and Eisenberg & Saltz, 1991, among many other sources that could be cited here. Amundson (2005, pp. 117-120) cites and discusses several additional studies with conclusions along these lines.

here is that any adequate account of disability will need to acknowledge *all* of these dimensions of the disability experience, rather than attempting to reduce it to one or another of them.

But how is such an account to be constructed? The key to this, as we will argue in this work, is to allow for multiple *levels of explanation* in our account. The basic idea here is that *each* of these conceptualizations is, in fact, correct—but at a *different level of explanation*. They do not contradict one another—as so many advocates on all sides of the debates suppose—but, rather, they complement each other and, collectively, serve to "fill out" a complete picture of the disability phenomenon. Thus, at one level of explanation—the biological level—disability *is* a "defect"; and at the psychological level, disability is, in a sense to be elucidated (and highly qualified) momentarily, a "tragedy"; but on the other hand, there is another level of explanation—the social—at which disability can rightly be seen as being a "neutral variation" and/or a "form of culture." The problem, then, is not with any of these conceptualizations of disability—as defect, tragedy, neutral variation, or form of culture, respectively—in and of themselves, but rather with the failure to recognize that they are *all* correct, *at different levels of explanation.* To put the point differently, the simple "conflict paradigm"—medical model *versus* social model; medical interventions *versus* social interventions, and so forth—ends up being, ultimately a false dichotomy: rather than "either-or," the reality is "both-and." These, then, are the claims to be made out in this work. We turn now to the process of developing and defending them.

B. Why the General Approaches are Inadequate

At this point we need to say a bit more about *why* the general approaches to modeling disability discussed earlier are inadequate. We have already rejected the moral model approach as leading to—or at least opening the door for—invidious and unwarranted inferences of responsibility or blame for being disabled, and in some cases, to unjust discriminatory practices grounded in such inferences. Therefore, we limit our attention here to the medical and social models. Moreover, for ease of exposition, we will for the moment focus our attention on the contrast between what we might term a "pure" medical and a "pure" (unconstrained) social model—though we will return to a consideration of the "constrained" version of the social model shortly. We turn first to a consideration of the pure, or "unconstrained" version of the social model.

The "unconstrained" version of the social model is clearly problematic. To see why this is so, consider the following thought experiment posed by Hans S. Reinders in the context of his critique of a Foucauldian analysis of disability, according to which there is no meaningful distinction to be made between "impairment" and "disability," by virtue of the fact that *both* terms are the product of a social construction.[37] The idea here is that on this account—which Reinders identifies as a nominalist one—the referent of 'impairment,' no less than 'disability,' is the linguistic structures and practices of a given society. Underlying this approach, on Reinders' interpretation, is a Foucauldian "antirealism" which involves "the uncompromising rejection of any suggestion that the language of impairment and disability refers to something 'out there,' a fact about the natural condition of human being that evokes a particular kind of response" (Reinders, 2008, p. 77). By way of response to this sort of approach, Reinders argues as follows:

> Following these ideas, Foucaldian theorists of disability can arrive at remarkable claims—patently false in my view—with regard to impairment and disability as natural realities. They categorically deny the existence of these realities independent from linguistic structures. For example, having noticed in the disability literature the ubiquitous distinction between "impairment" and "disability" as denoting two separate domains, Barry Allen asserts that "nobody is impaired all on her own, through a naturally occurring deficit that her body bears as a biophysical property." Regarding this claim I invite the reader to consider the following thought experiment. Imagine a blind Robinson Crusoe on his deserted island. For the sake of the argument, imagine also that Robinson has no knowledge of ever having been able to see; hence "blindness" does not mean anything to him. Does he have a visual impairment or not? One thing is immediately clear: Robinson does not know he has an impairment. But does it also follow that he has none? If we could observe him, what would we see? Presumably we would see a man using a stick to get by on his island without stumbling, or maybe he would use his hands, stretching out his arms for the same purpose—the way people do when they are blindfolded. So we would observe that Robinson was blind based on his behavior. The Foucauldian theorist

[37] That is, neither term falls under any biological constraints at all. This is a crucial feature of social construction of the Foucauldian variety.

> may well ask what this proves, other than that we are in the position to suppose "blindness" because *we* know the concept. At any rate, they would argue, we would have to say that his behavior does not depend on our supposition of blindness. Instead, we should say that his behavior is an adequate response to a condition he finds himself in. Following Foucault's concept of power/knowledge as creating certain possibilities for action, the Foucaldian theorist would have to say that the perception of Robinson's behavior is a response, not to a natural condition, but to our ability of "seeing" and "saying" blindness. That is obviously false, for the following reason: it conflates the distinction between knowing and being (Reinders, 2008, pp. 77-78, quoting Allen, 2005, p. 94).

In other words, Reinders is saying, it is one thing to *be* blind; it is another thing altogether to *know* that one is blind—that is, social constructions of disability are (in fact) constrained by biological realities.[38] If this line of reasoning is cogent, as it seems to be, then it follows that we must reject an unconstrained social model. Therefore we will, henceforth, limit ourselves to the medical and constrained social models.

At first glance, each of these remaining models appears to have something going for it. On the one hand, as we have argued in this work, impairment *does* appear to be an objective ontological reality, a fact which the medical model captures well. Unfortunately, as we have also shown, the medical model tends to discount the role of social and environmental factors in the disability phenomenon. The constrained social model, on the other hand, has the virtue of acknowledging impairment as a real ontological reality. Nevertheless, constrained social modellists tend to cast *disability* itself exclusively as an "add-on" to impairment, the idea being that if only society were changed sufficiently, persons would no longer be disabled.[39] But this, too, as much as the unconstrained social model, fails to take into account the role that impairments

---

[38] Connecting this argument up with a point raised earlier, we might argue that the state of being blind, because it is an *impairment* (whether or not it is also a *disability*), is always a "problem for the individual," whether or not it is also a "problem for the community."

[39] Cf. the following statement, made by UPIAS in 1976:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976, p. 3, quoted in Oliver, 1996, p., 22, quoted in turn by Shakespeare, 2006, p. 12).

play in bringing about disability. Indeed, as we noted earlier, for many individuals with impairment, their impairment(s) is/are the most "salient" feature of their everyday experience (Shakespeare, 2006, pp. 41-42)—experiential features which, in many cases, simply cannot be eliminated by any amount of social change. By process of elimination, then, we are forced to the conclusion that *none* of these approaches, taken by themselves, will work; we are therefore led to search for an alternative approach that will better accommodate all these different dimensions within its ambit. The claim of this work is that a "biopsychosocial" approach gives us what we need in this regard, particularly by encompassing the strengths of the medical and constrained social approaches, respectively, while also avoiding their weaknesses.

C. The Biopsychosocial Approach: Multiple Levels of Explanation

The key to a BPS approach to disability is that it understands disability as a phenomenon that can only be—and therefore must be—explained on *multiple levels of explanation*. Here, the basic idea is that each of the individual conceptualizations discussed above is true (in some sense), but at different levels of explanation—in ways that will be developed and nuanced as the work progresses—and therefore necessary for an adequate or complete account of disability. Thus, because disability is *grounded in* an objectively real impairment, it is correct to say, at the *biological* ("bio") level of explanation, that disability is (or involves) a "defect" in the biomedical sense.[40] At the *psychological* ("psycho-") level of explanation—i.e., the phenomenological level at which the individual is aware of and experiences the condition of being disabled— disability is a "tragedy" in the (highly qualified) sense that being disabled is a negative thing, independently of the world, to have happen to one. It is a "tragedy" in the sense that it involves some kind of *loss*—even if only the loss associated with the functional limitation imposed by impairment—*not* in the sense that the disabled individual is thereby of necessity relegated to a state of emotional distress or unhappiness.[41] In other words, given its ontological grounding in impairment, "disability"

---

[40] In other words, while disability involves more than just impairment, it does *involve* an objectively real impairment, and in that sense is a "defect," biomedically speaking.

[41] It should be acknowledged here that the word "tragedy" is potentially a loaded term, certainly one that many disability rights advocates would find offensive. Hence, we go out of our way here to nuance the sense in which the word is applicable. The basic point, to be clear, is simply that disability is a "bad" thing, *all other things being equal*, to have happen to one—which, in turn, partly explains which why people try to avoid it. This caveat having been issued, however, it is also worth noting that since DR advocates such as Oliver (1990) and others have faulted the medical model for

involves an objective loss of some sort—and is, in that (perhaps very attenuated) sense a "tragedy" for the individual, an occurrence that, all other things being equal,[42] we would not desire either for ourselves or for others and is therefore to be avoided if possible. The underlying conceptual point here is that "disability" is always identified in terms of norms involving ideals of form and function, freedom from pain, life span, and so forth, such that to fall short of such norms is deemed, objectively speaking, a "loss" or "tragedy"—however much that loss/tragedy might be mitigated by social responses. Finally, however, as this last point suggests, disability can be understood, on the *social* level, as (at least potentially, if not always) a "neutral variation" in the sense that the *effects* of impairment can, in principle, be neutralized given sufficient social responses (the neutral variation view will be discussed further in Ch. 4; the second part of Ch. 5 will attend to issues having to do with social responses to disability). Additionally, disability can at this level of explanation also be understood as a "form of culture" in the sense that the disabled condition can (at least potentially) constitute grounds for personal, social, and cultural identity, as well as for common bonds, unified political action, and so forth (this will be discussed further in Ch. 5).

Ultimately, then, what gets missed in the debate is that each of the conceptualizations (defect/tragedy/neutral variation/form of culture) is correct, at a different level of explanation. The problem is thus not with the conceptualizations *per se*, but with the failure to recognize (1) that they are *all* correct, and (2) that there are different levels of explanation (at which the individual conceptualizations are accurate). The *explanatory* problem with the other approaches to modeling, then, is that they attempt to provide a reductive account of a phenomenon that can only be adequately explained on multiple levels. Given the foregoing, it would appear that we need an approach to modeling disability that incorporates *all* of the elements—biological, psychological, and social—to which the moral, medical, and social models individually point.

Taking stock, we can summarize our argument up to this point as follows. The moral model approach is problematic because it lends itself too easily to invidious and unwarranted

---

conceptualizing disability in terms of "tragedy," it is relevant in this present context to use the term in order to show how that term is, in at least this highly qualified sense, appropriate.

[42] As we have noted on numerous occasions throughout this work, of course, things are not always "equal." There can, for example, be certain occasions on which being deemed "disabled" turns out to be beneficial to the individual. Generally speaking, however, disability is considered a negative state, one to be avoided if possible.

attributions of moral responsibility for being disabled, as a consequence of which it opens up those with disabilities to stigmatization and other forms of unjust discriminatory practices. The (pure) medical model approach is problematic because it fails to acknowledge the role of social-environmental factors in the disablement process. Conversely, the social model approach—in both its constrained and unconstrained forms—fails to do justice to the reality and impact of impairments in the lives of many disabled persons. Given the failure of each of these individual approaches, we need an alternative approach that better captures all of these aspects of the disability phenomenon. Arguably, a *biopsychosocial* approach, one which involves *multiple levels of explanation*—where each of the individual characterizations of disability are accurate, but at a different level of explanation—provides us with just what we need.

We now have the basic framework in place with which to provide a rough "map" of the territory to be explored in the rest of this work. Key to this exploration will be a recognition of a (rough) parallel that can be drawn between the *levels of explanation* in terms of which a biopsychosocial approach explains the disability phenomenon, on the one hand, and the *domains of philosophical explanation* to which this work has repeatedly drawn attention, on the other. The basic idea here is as follows. At the *biological* level, a BPS approach to disability will offer an *ontological* explanation of the realities involved in the disability phenomenon, primarily in terms of medical-scientific factors. At the *psychological* level, a BPS approach will offer a *non-moral normative* explanation, primarily in terms of non-moral normative values. And, at the *social* level, a BPS approach will offer a *moral normative* explanation, primarily in terms of moral-political and sociopolitical considerations.[43] The parallel posited here can be represented schematically as in the following diagram:

[43] Another way to put these distinctions is to say that the explanaans in an ontological/medical-scientific explanation appeals to medical and scientific terms (concepts, entities, etc.) in order to explain (account for) the explanandum, while a non-moral normative explanation appeals to normative values that are non-moral, and a moral normative explanation accounts for its explanandum by appeal to moral values.

Level of Explanation in BPS Account	Domain of Philosophical Inquiry	Explanation given in terms of...
Biological	Ontological	Medical-scientific factors
Psychological	Non-moral normative (including epistemology)	Non-moral normative values (aesthetic, cultural, epistemic)
Social	Moral normative	Moral-political/socio-political considerations

Table 2.1 Relationship between domains of inquiry and levels of explanation in BPS account.

In this work we will be concerned mostly with the first two levels—namely, the "biological" and "psychological" levels, which (roughly) correspond to the *ontological* and *non-moral normative* domains of philosophical inquiry to which we have drawn attention. We will, however, turn our attention in the second half of chapter 5 to the *moral normative* domain of philosophical inquiry, which concerns itself with issues related to the "social" level of explanation (in the BPS account).

V. GETTING BEYOND THE "MEDICAL-VS.-SOCIAL MODEL" IMPASSE: A SYNTHETIC MODEL OF DISABILITY...?

A. The "Medical-vs.-Social Model" Impasse

We have noted already that the contemporary literature on disability is typically cast in terms of a conflict between the medical and social models, and also that that conflict has increasingly come to be seen as being at an "impasse." Clearly, if we are to arrive at a comprehensive analysis of the concept of disability, we will need to find a way forward beyond that impasse. In this part of the chapter, we turn our attention to the prospects for finding such a way forward.

B. The ICF as an Attempt at Synthesizing the Medical and Social Models

The ICF was explicitly designed to be a synthesis of the medical and social model approaches to disability. As the introductory page on the World Health Organization website puts it, the ICF "takes into account the social aspects of disability and does not see disability only as a

'medical' or 'biological' dysfunction" (WHO, "International Classification of Functioning, Disability, and Health"). In a key section of the ICF's text, the framers indicate the relationship that they envision between the ICF, on the one hand, and the medical and social models, on the other:

> A variety of conceptual models has been proposed to understand and explain disability and functioning. These may be expressed in a dialectic of 'medical model' versus 'social model'. The *medical model* views disability as a problem of the person, directly caused by disease, trauma, or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behaviour change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy. The *social model* of disability, on the other hand, sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue.
>
> ICF is based on an integration of these two opposing models. In order to capture the integration of the various perspectives of functioning, a 'biopsychosocial' approach is used. Thus, ICF attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual, and social perspective (WHO, 2001, p. 20).

On this understanding, "[d]isability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external

factors that represent the circumstances in which the individual lives" (WHO, 2001, p. 17). Functioning and disability alike are, on this view, "conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors" (WHO, 2001, p. 8). The ICF is thus premised on an interactive model, according to which the various conceptual components (health condition, body functions and structures, activities, and participation) all interact in various ways with one another, as well as with various contextual features, both personal and environmental.

Since the ICF is relatively new, it is not yet clear whether or not, or how, it will affect the worldwide collection of data on health and disability, as well as what kind of impact it will have in the clinical setting. What may be more significant, in the final analysis, is the underlying philosophical approach taken by the framers of the ICF; as Bickenbach puts it, "[t]he 'biopsychosocial' model of the ICF may well be more influential than the classification system itself in the long run" (Bickenbach, 2006, p. 968). Recall, in this regard, that the ICF conceptualizes "disability phenomena (that is, impairments of body function or structure, activity limitations, and participation restrictions)" as "outcomes of interactions between features of the person, including background health condition, and environmental factors" (Bickenbach, 2006, p. 968). In other words, the ICF is "based on a *multidimensional* and *interactive* model of human functioning and disability" (Bickenbach, 2006, p. 969, italics in original).[44] The important upshot of this, according to Bickenbach, is that the ICF can be understood as a "synthesis of what is useful in both the medical and social models of disability, without making their mistake of reducing the whole, multidimensional notion of disability to one of its aspects" (Bickenbach, 2006, p. 968).

C. The Need for an Improved Theoretical/Philosophical Framework for Understanding Disability

Although it is true, as we have noted along the way, that some degree of nuance can be introduced into the approaches discussed here—e.g., a medical model approach can consider the relevance of social-environmental factors to addressing medical problems—nevertheless the *overall* focus of each of the general approaches discussed above does indeed appear to be

[44] In this respect, as Bickenbach points out, the ICF closely resembles Saad Nagi's model.

moral, medical, and social, respectively. To the extent that each of these approaches focuses on these dimensions to the exclusion of the others, to that extent each approach will be problematic. Therefore, we need an approach that encompasses the strengths of each of the others, while avoiding their weaknesses. For example, we need to be able to acknowledge that people can bear moral responsibility for *becoming* disabled (e.g., as the result of certain risky behaviors), while avoiding the temptation to blame people for *being* disabled, and especially to resist the temptation to stigmatize or unwarrantedly discriminate against such individuals in response to their disabled condition. Similarly, we need a way to acknowledge the reality of impairment (as on the medical model), while not ignoring the reality of social and environmental factors in the production, exacerbation, and/or maintenance of disability (as on the social model). Any attempt to reduce our account of disability to just one or another of these three types of approaches is bound either to be fatally flawed (as in the moral model) or to miss important aspects of the disability phenomenon that ought to be captured by an adequate account (recall our discussion, in the Introduction, of the desiderata for a "good" explanation). Arguably, a "biopsychosocial" approach provides just what we need. As we saw in the previous subsection, the ICF is promising in this regard; nevertheless, detractors have pointed to certain weaknesses in the ICF's framework (Bickenbach, 2006). Consequently, there is a need for further conceptual and philosophical work. This project is devoted to the task of developing the philosophical underpinnings for an adequate "biopsychosocial" approach to disability.

D. Toward a "Synthetic" Model of Disability: The Biopsychosocial Approach

The foregoing suggests a case for the need to move beyond the "medical versus social model" impasse. Ideally, what we need is a synthesis that combines the respective strengths of the various models, while avoiding their problems. Arguably, such a "synthesis" can be found in what we might term a "biopsychosocial" model of (or approach to) disability. The next chapter is devoted to developing an account of what such an approach might look like.

VI. CONCLUSION

In Chapter 1, we demonstrated that there is *prima facie* reason to think that any adequate account of disability will need to include at least one conceptual term that involves *extrinsic*

predications—and, moreover, that that term will most likely be the "outcome term," that is, 'disability' or one of its equivalents. In other words, any adequate account of disability will need to make reference not only to features that are intrinsic to the individual, but also to features that are extrinsic to her as well. Further, the continual reappearance of appeals to norms—whether implicit or explicit—at various theoretical levels gave us *prima facie* reason to suspect that any adequate account of disability will inevitably be at least a partly normative one—that is, a strictly non-normativist account of disability is unlikely to succeed.

Chapter 2 gave us a number of additional elements to add to our initial sketch of what an adequate account of disability might look like. For starters, our discussion of the *impairment/disability* distinction demonstrated how difficult it is to divorce "disability" from "impairment"; without some grounding in an (ontologically real) impairment, "disability" quickly becomes a vague and unworkable notion. There is, further, an inextricable "interpenetration" of biological, psychological, and social factors in the identification and labeling of states of affairs as 'impairment' and 'disability.' Given these observations, we have *prima facie* reason to suspect that any adequate account of disability will involve some sort of ontological realism—specifically, with respect to the objective reality of impairment as such. Our exploration of the *disability/handicap* distinction served two functions: (1) first, it provided us with license to limit our subsequent discussion to "impairment" and "disability" rather than "impairment-disability-handicap," while at the same time (2) providing us with further support for the claim that "disability" is inherently an (at least partially) value-laden, normative concept. Indeed, as we saw, *both* terms involve intrinsic and extrinsic predication, and there is always a dynamic interplay between the two types of predication.

Finally, our exploration of the three major types of approaches to modeling disability—the moral, medical, and social model approaches, respectively—demonstrated how each suffers from a fatal flaw and/or misses something important that ought to be captured by an adequate, fully-comprehensive account. The moral model approach is fatally flawed because it too easily lends itself to invidious, unwarranted inferences of moral responsibility for being disabled. The medical model approach, as we saw, in its tendency toward an exclusive focus on medical causes of and

remedies for the problem of disability, is subject to the criticism that it misses important social and environmental factors that play a role in causing and exacerbating disability. As one might expect, the social model is subject to precisely the opposite criticism—namely, that in focusing its attention on social and environmental causes of disability, it misses the reality and significance of (biological/anatomical/physiological) impairment. Given the failure of each of these three general types of approaches to modeling disability, this gives us *prima facie* reason to think that we need some better approach, one that includes the strengths of each of those other approaches while avoiding their weaknesses. In this regard, we suggested that a "biopsychosocial" approach may very well supply just what we need.

These, then, are the themes that remain to be developed—and defended—in subsequent chapters. We begin this process in chapter 3 by sketching a tentative picture of what such a "biopsychosocial" account might look like with respect to disability. In chapter 4 we defend the need for a realistic ontology with respect to impairment and disability, and explore some of the implications of adopting such an ontology. Chapter 5 is concerned with exploring some of the various normative values that enter into accounts of impairment and disability, as well as some of the moral considerations that enter into questions about how society ought to respond to disability. Chapter 6 discusses some of the sociological and political issues that are pertinent to understanding the concept of disability. Finally, Chapter 7 pulls together the various individual threads of the work to draw some general conclusions and explore some of the implications of this study for our understanding of the nature of disability, the future of disability studies and the disability rights movement, and the relationship more generally between the disabled and the broader society.

Chapter 3

THE CONCEPT OF DISABILITY: DEVELOPING A THEORETICAL FRAMEWORK

I. INTRODUCTION

Having analyzed and assessed some of the most important specific models of disability in the literature (Ch. 1), as well as the general approaches to modeling disability (Ch. 2), we are now in a position to move on, in this chapter, to the positive task of developing a theoretical framework within which to understand the concept of disability. This task is approached from the vantage point of the work done in chapter 2, where, after rejecting the viability of the moral and unconstrained social models of disability, we also showed that the medical and constrained social models are problematic—leaving us with the need for a more adequate approach to modeling disability. The present chapter has two major goals. First, building on the critical appraisal in chapter 2, this chapter seeks to show that the "conflict" (whether real or imagined) between the medical and social models stems from a failure to distinguish sufficiently among different kinds of explanation of impairment and disability—namely, ontological (involving reference to medical-scientific factors), non-moral normative, and moral normative explanations. Second, the chapter aims to show how a BPS approach keeps these explanations distinct and produces a comprehensive picture of disability. The claim here will be that the BPS account can explain impairment and disability more adequately than can the medical or constrained social models by themselves. In particular, the BPS approach underwrites a socially constructed concept of disability but only under biological and psychological constraints, in a way that incorporates the insights of both the medical and constrained social models, but avoids their respective weaknesses.

With the foregoing objectives in view, the chapter begins with a brief appraisal of the disability literature, focusing particularly on two problematic features of that literature. This is followed by a discussion of the variability of different types of disabilities, with a view toward identifying some of the conceptual and methodological implications of that variability; and by a comparison of concepts of disease and illness, on the one hand, and concepts of disability on the

other. The thrust of this latter portion of the chapter is to establish that there are relevant analogues between these different categories of concepts. This sets the stage for the subsequent section, the burden of which is to introduce and explicate George L. Engel's "biopsychosocial model of disease," and to show how it provides useful theoretical resources for developing an analogous "biopsychosocial" approach to disability. This in turn serves as a springboard for developing, in the next section, the general contours of such an approach to disability. The final section pulls together the various threads of the chapter's argument in support of the overall conclusion that a BPS approach offers a more adequate explanation of impairment and disability than does any of its rivals.

II. A BRIEF APPRAISAL OF THE CURRENT LITERATURE ON DISABILITY

This portion of the chapter is concerned with the negative project of identifying and diagnosing certain problems, or confusions, in the current literature bearing on disability, particularly the literature focusing on models of disability. This task involves identifying two common features of the literature on models of disability, and seeking to show why those features are problematic in several important ways. These features are (1) the assumption of a fundamental incompatibility between the "medical" and "social" models of disability, and (2) a conflation of (causal) explanatory accounts and social justice claims, respectively.[1]

A. The relationship between the medical and social models: fundamentally incompatible...?

As we have seen, on the medical model the *source* or *causal locus* of disability is held to be in the individual deemed to have a disability or to be disabled. Specifically, "disability" is considered a "defect"—anatomical, physiological, etc.—in the individual who is disabled. This

[1] Two important caveats are in order at this point. First, when theorists advocate a "social model" approach to disability, it is not always clear whether they are advocating a *constrained* or *unconstrained* version of the social model. For this reason, comments addressed toward the "social model" will sometimes be made with the constrained version in mind, other times with the unconstrained version in mind. Second, and more significantly, the label "medical model" is a term used principally by *social model* advocates to demean or disparage approaches to disability that explain it primarily in medical terms. It is difficult, however, to find theorists who *themselves* use the label to describe their own theory, and it would certainly be unusual (perhaps impossible) to find a theorist who explicitly condoned stereotyping and/or stigmatization of the disabled, even if at a theoretical level they preferred to explain disability in primarily (or even exclusively) medical terms (Shakespeare et al., 2006, p. 1103; Shakespeare, 2006, p 18). So while it is a legitimate question (one to which we return in Chapter 6) to ask whether or not the medical model has the *effect* of stigmatizing/stereotyping (e.g., by virtue of its characterization of disability in medical terms), the label itself should be used with caution, or at least with an awareness of these difficulties. For better or worse, however, it appears that we are "stuck" with these labels, at least for now.

contrasts with the "social model" of disability, according to which the causal locus of disability is to be situated in social structures and practices that have the effect of excluding or marginalizing—and thereby disabling—those whose physiological or cognitive constitutions render them "different" than the majority population.[2] It is a commonplace in the literature to assume, as an unargued premise, that these models are fundamentally opposed to or incompatible with one another (Silvers, 1998).

Arguably, this is an erroneous assumption, one which stems from a failure to distinguish adequately between different *kinds* of explanations and concerns—ontological (medical-scientific), non-moral normative, and moral normative, respectively. To see this, consider again the reconstruction of the medical model offered by social model theorist Anita Silvers, which we discussed in Chapter 2. As Silvers explains it, since on the medical model disability is caused by "physiological or mental deficit," the medical model therefore "...fixes on reducing the numbers of people with disability by preventative or curative medical technology" (Silvers, 1998, p. 59). However, when Silvers claims that *because* the medical model identifies "physiological or mental deficit" as the cause of disability, the model *therefore* "...fixes on reducing the numbers of people with disability by preventative or curative medical technology" (Silvers, 1998, p. 59), this appears to be a misunderstanding of the import of the medical model—and, in turn, an example of the failure to distinguish between different kinds of explanation/concern to which this study seeks to draw attention. For even if disability is *caused by* "physiological or mental deficit," there may in fact be different ways to *respond to* disability—which modes of response may or may not include a focus on "preventative or curative medical technology." Arguably, what the medical model offers is a *medical-scientific explanation*, rather than a *moral normative explanation* or a *moral normative prescription*; to conflate the two is, quite simply, to mischaracterize the medical model.

To see more clearly why the assumption of a fundamental incompatibility between the two models is mistaken, recall that on the social model, disability is *caused by* discriminatory or oppressive social structures and practices; hence, Silvers and others claim, the "solution" to the "problem" of disability lies in social reform *rather than* either "repair" of or "compensation" to those

[2] For an important formulation of the social model, one that is frequently cited in the literature as a touchstone for further discussion, see Oliver, 1990.

who have disabilities. Moreover, they claim, the medical model "fixes on" (to borrow Silvers' terminology again) *medical,* individualized solutions to the problem of disability *rather than* social reform. Given these claims it would indeed seem to follow that the two models are incompatible with one another: one calls (exclusively) for repair/compensation of *individuals,* the other calls (exclusively) for *social reform*—or so it would seem. But of course, if it should turn out that the medical model simply offers a *medical-scientific explanation* for disability, in terms of underlying anatomical structures and pathological processes, and that it offers nothing *more* than this—that is, it does not (in itself) provide a moral-normative prescription as to how we ought to *respond* to disabilities (either individually or as a society)—then it seems clear that the two "models" are not inherently incompatible with one another: after one has given a medical-scientific account of disability, it remains open to make further arguments (one way or another) concerning how best to *respond to* disability.

Our comments thus far have focused primarily on the first of the "problematic features" that are exemplified in much of the contemporary literature bearing on the nature of disability—namely, the assumption of a fundamental incompatibility between the "medical" and "social" models of disability, which, we have suggested, stems in turn from a failure to distinguish sufficiently between different kinds of explanation and concern—for example, between medical-scientific (causal) explanations/concerns and moral-normative explanations/concerns. Arguably, the passage quoted above also illustrates the second "problematic feature" identified above—namely, the conflation of (causal) explanatory accounts and social justice claims. We turn now to an explicit consideration of this claim. In brief, the idea to be developed here is that there is no *necessary* connection between conceptualizations of disability and specific social justice claims.

B. Conflation of causal explanatory accounts and social justice claims

It is typically taken to be the case that there is a close relationship between models of disability and theories of social justice. Thus, for example, sociologist and social model theorist Michael Oliver claims that

> [a]s far as disability is concerned, if it is seen as a tragedy, then disabled people will be treated as if they are the victims of some tragic happening or circumstance. This

> treatment will occur not just in everyday interaction but will also be translated into social policies which will attempt to compensate these victims for the tragedies that have befallen them.
>
> Alternatively, it logically follows that if disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared toward alleviating oppression, rather than compensating individuals. It almost goes without saying that at present, the individual and tragic view of disability dominates both social interactions and social policies (Oliver, 1990, pp. 2-4).

This passage appears to constitute an example of conflation between causal explanatory accounts and social justice claims/prescriptive imperatives. Why, for example, should we think that these conceptualizations of disability *will* either result in attempts to compensate, on the one hand, or in attempts to alleviate oppression *rather than* compensation of individuals, on the other hand? Arguably, the alleged necessary connection between these is questionable.

To see this more clearly, it will be helpful to consider why it is so frequently taken to be the case that there *is* a close relationship between models of disability and theories of social justice. For present purposes, that idea can be summarized in the following way. Among other purposes, models of disability seek to locate the causal source (or locus) of disability. In doing so, they also apparently imply an answer to the question of the appropriate locus of responsibility for the amelioration or elimination of disability (on the assumption, of course, that disability is in fact something that *should* be ameliorated or eliminated). Thus, if the causal source of disability is a problem (anatomical, physiological, etc.) *in the individual* who has a disability, then this would seem to call out for some sort of *medical* response in an effort to eliminate or ameliorate the disability (see Oliver, 1990). In seeking to achieve this objective, medical treatment will aim to restore or improve lost *functioning,* with a view toward improving the individual's overall welfare, or well-being. This lends itself, in turn, to a theory of social justice that emphasizes equality of *welfare*: if disability is seen as a defect in the individual that diminishes the individual's well-being,

then the appropriate response on the part of society would presumably be to attempt to "fix" the individual so as to restore her (to the extent possible) to her previous level of well-being.

By contrast, if disability is conceptualized as being caused by the failure of society to adapt to the limitations of those with disabilities, as advocates of the social model contend, then the appropriate response would seem to be social reform rather than medical intervention. Hence, the social model of disability would lend itself to a theory of justice that emphasizes equality of *opportunity*: persons with disabilities are to be "equalized" by changing social structures so as to ensure that they have opportunity to flourish in society despite their limitations.

There is yet another option—namely, embracing a theory of social justice that emphasizes equality of *resources*.[3] One could conceivably be either a medical model theorist or a social model theorist and embrace this latter type of theory (of social justice). If, for example, one claims that the source of disability is to be located in a "defect" in the individual, then one might argue, in turn, that the appropriate response is to "compensate" materially those individuals who have fared poorly in the "natural lottery" through no fault of their own. Alternatively, one might locate the causal etiology of disability in "oppressive" or "discriminatory" social practices (Oliver, 1990; Silvers, 1998), yet still insist that the best way to respond is to provide disabled persons with additional resources sufficient to ameliorate the effects of such oppression.[4]

Finally, one might argue that the proper response to disability—conceptualized as a diminishment of one's *capabilities* for functioning in a way that enhances human flourishing—is to restructure society in such a way as to maximize the capabilities for flourishing of persons with disabilities. This would lend itself to a theory of social justice emphasizing equality of *capabilities*

---

[3] For more detailed theoretical discussion of theories of justice, particularly those emphasizing equality of welfare, opportunity, and resources, see Arneson (2002a; 2002b), Dworkin (1981a; 1981b; 2000), and Gosepath (2006). See also the sources listed in note #5, below.

[4] My analysis of the possibilities here differs somewhat from formulations frequently found in the literature. Advocates of the social model will, of course, reject the final possibility mentioned, insisting that such an approach would merely ratify unjust social practices. Still, even granting this point, many of these theorists seem not to have recognized that *even if* one locates the causal source of disability in "social restriction" or "oppression," it may still be possible that the most *efficient* or *effective* way to enable a person to overcome the effects of such discrimination is through direct compensation rather than through attempting to reform social structures, unjust though those structures may be. Of course, I am not *endorsing* this latter possibility; I merely point out its conceivability, and note that many social model theorists seem not to have recognized this.

(what Martha Nussbaum, building on the work of Amartya Sen, has termed the "capabilities approach").[5]

It thus appears—at first glance, anyway—that how one *conceptualizes* disability will have important implications for the theories of social justice one embraces and the public policies that one goes on to endorse or advocate with respect to disability. However, there may very well be reasons to question the apparent closeness of these relationships. For one thing, as the brief discussion above illustrated, one can conceive of a number of different ways in which models of disability and theories of social justice might relate to one another; *prima facie*, there seems to be no immediate and obvious, much less a necessary connection, between a given model of disability on the one hand, and a given theory of social justice on the other.

More importantly, one might run "social justice"-type arguments in divergent directions, *regardless* of which "model" of disability one embraces. One might, for example, plausibly appeal to different theories of distributive or social justice depending on the type of disability at hand, the anticipated prognosis, the relative costs of accommodation, and so forth. When faced, for example, with a choice between expending great resources on a severely disabled individual who is likely to die at a very young age (as a result of that disability), versus expending the same amount of resources (perhaps over a longer period of time) on a disabled individual who is likely to enjoy a "normal" lifespan, there is no *obvious,* immediate answer as to which choice ought to be made.[6] Perhaps we ought to take a utilitarian stance and direct the resources toward that individual (presumably, the second) who would derive the greatest "benefit" from them; alternatively, we might take a Rawlsian approach and insist that the resources ought to be directed toward the "worst off" individual (in this case, the one who is likely to die at an early age due to severe disability). Of course, the point for present purposes is not to endorse one option over the other, nor to argue the case in either direction. Rather, the salient point at present is that

---

[5] Broadly speaking (and ignoring for the moment fine-grained nuances in their respective views), we can identify the following as representatives of each of these general types of approach: Norman Daniels (equality of welfare), Anita Silvers (equality of opportunity), David Wasserman (equality of resources), and Martha Nussbaum (equality of capabilities). There are, of course, important similarities and differences between these different approaches, to which we will not attend here. See Silvers, 1998; Daniels, 1985; Daniels, 1990; Daniels, 2007; Wasserman, 1998; and Nussbaum, 2006.

[6] See H.T. Engelhardt, Jr.'s suggestion of a *reductio* of social justice arguments along these lines, in his (2009).

models of disability, as such, would hardly seem to be sufficient to settle *this* dispute.[7] Put differently, the claim here is that there is no necessary entailment between a given conceptualization of disability and a particular moral normative stance involving specific social justice claims.

At the end of the day, then, the claim that there is a necessary connection between any given conceptualization of disability and a given theory of social justice is untenable. And yet, as we have sought to illustrate above, this claim is frequently taken for granted in the contemporary literature on the nature of disability. To the extent that this is the case, I want to insist, it is a mistaken conflation of explanatory (causal) accounts and social justice claims. And the upshot, for our purposes, is that "models" will not tell us much either way about social justice claims. We ought not to look to models of disability to give us guidance in that area. Nor should alleged "social justice consequences" be taken to *invalidate* the legitimacy of a given model of disability—a move often made by social model theorists over against the medical model. Rather, models of disability may (or may not) help us to understand the relevant *causal* factors underlying various states of affairs identified as "disability" ("Why?"), as well as the nature of such states themselves ("What?"). That is to say, they answer either the "What?" question or the "Why?" question, but not the "What now?" question.

III. CONCEPTUAL AND METHODOLOGICAL IMPLICATIONS OF THE VARIABILITY OF DISABILITY

One important point that this study seeks to underscore is that any adequately comprehensive account of disability needs to be sensitive to the wide variations *among* disabilities. Since disabilities range widely in terms of their biological, psychological, and social dimensions—as the general taxonomy presented in the Introduction to this work illustrates—we need an account that encompasses these various dimensions. At the same time, we also need an account that allows us to focus our attention more directly one on or another of these dimensions, when appropriate, without excluding the others entirely. This is because in some cases of disability, the "medical" aspects may be more prominent or salient, given certain

[7] I am grateful to Baruch Brody for alerting me to the issues discussed in this paragraph.

purposes or goals (e.g., of the individual, of society, etc.); in other cases, psychological aspects may dominate or be considered more salient; and in still other cases, social aspects may take precedence. Here one might think, for example, of the differences between such conditions as chromosomal deletion disorder and Down syndrome, on the one hand, and deafness on the other. One might argue that "medical" features are more prominent in explaining and/or responding to the former conditions than is the case with respect to the latter condition, while yet not wishing to eliminate altogether either "psychological" or "social" aspects from one's account. (Of course, one might also argue, to the contrary, that either social or psychological factors predominate over the other two in these cases; the point for present purposes is simply that these sorts of arguments can in fact be made.) One of the advantages of a biopsychosocial approach to disability is that it allows us to hold all of these elements together in a single account, while still allowing conceptual room to argue that one or more of the individual elements is more "salient" in a given case.

There is yet another, related advantage to be found in the biopsychosocial approach. In the previous part of this chapter, we suggested that there is no *necessary* connection between conceptualizations of disability and specific theories of social justice. That having been said, *given* a specific theory of social justice, the type of disability involved may very well be relevant. For example, returning to the case we considered previously, utilitarianism might recommend expending resources on the individual who would live a "normal" lifespan, *rather than* the newborn who would likely die young.[8] Further, medical interventions (as would be recommended by a "medical model") may in fact be more appropriate for some types of disability, whereas social change (as recommended by a "social model") account may be more appropriate for other types of disability. At the same time, any adequate response to disability is likely to involve some intervention at all relevant levels—biological, psychological, social, etc. In the final analysis, the advantage of a biopsychosocial approach is that it is able to accommodate all of these realities, without forcing upon us an arbitrary—and false—choice between *either* an exclusively "medical"

[8] As before, this sentence should be interpreted as *illustrative,* rather than an *endorsement* of such a position.

understanding of and/or response to disability, on the one hand, *or* an exclusively "social" understanding of and/or response, on the other.

IV. A COMPARISON OF CONCEPTS AND CONCEPTIONS OF DISEASE AND ILLNESS WITH CONCEPTS AND CONCEPTIONS OF DISABILITY

This portion of chapter 3 is concerned with the positive task of demonstrating that the resources of the philosophy of medicine can be useful in moving us beyond the "medical vs. social model" impasse, and thus in providing us with a fuller, more comprehensive understanding of the nature of disability. The central claim here is that there is a significant parallel between considerations raised when investigating the nature of disease and illness, on the one hand, and disability on the other. Specifically, we can raise the same sorts of questions—ontological, non-moral normative (including epistemological), and moral normative—with respect to disability, on the one hand, as we can with respect to disease and illness, on the other. The significant upshot of this is that it helps to motivate the remainder of the study, which is engaged in the project of developing a comprehensive analysis of disability in terms of these domains of philosophical inquiry.

In an effort to establish this parallel, we will compare concepts of disability with concepts of disease and illness, as these have been explored in the philosophy of medicine. To that end, we shall attend explicitly, in Chapter 4, to disputes regarding the proper role, if any, of values and norms—of both the moral and non-moral variety—in the identification of states of affairs as states of illness and disease, and by extension states of disability. This exploration will be launched by way of a discussion of the works of Christopher Boorse (1997) and H.T. Engelhardt, Jr. (1996). In that context, we will argue for a weak normativist position in the normativist-nonnormativist debate vis-à-vis the value-infectedness of determinations of illness and disease, coupled with a broadly "objectivist" position in the naturalist-nonnaturalist debate vis-à-vis illness/disease. By way of preview, these respective disputes can be characterized, in very general terms, along the following lines.

A. Naturalism/Non-Naturalism and Normativism/Non-Normativism: An Introductory Overview

The position one ultimately embraces on the value-neutrality of concepts of health, illness, and disease will depend on the answers one gives to each of a succession of questions. One might begin by asking the question, "are diseases natural kinds?"[9] If one answers this question in the affirmative, then one will be a "naturalist" with respect to this question. If one rejects the notion that diseases are natural kinds, then one will be committed to some form of non-naturalism—specifically, to some version of "instrumentalism" (or "conventionalism"), according to which diseases are best understood as being (merely) instrumental classifications. Hence, the first axis of debate with respect to this question can be identified in terms of "Naturalism" versus "Non-naturalism" (also known as "conventionalism" or "instrumentalism").

Returning now to the naturalist position, one might query whether a strictly *neutralist* account of disease is adequate. According to the neutralist, determinations of health and disease are *entirely* value-free: there is absolutely no ingression of non-epistemic values[10] of *any* kind. If one thinks that the neutralist account of disease concepts is sufficient, then there is no further question to be asked: one has fully accounted for the nature of disease concepts. If, on the other hand, one is a naturalist but thinks that the neutralist account is *not* sufficient, then one will be committed to what we might term Objectivism: one will affirm that "values" do enter into determinations of health and disease, but will locate those values (at least partly) in nature rather than in (merely) instrumental classifications.[11] Thus, one who takes the Objectivist position will be

---

[9] Natural kinds are things that have essential properties; objects belonging to the same natural kind have those essential properties in common (Sober, 1995). This shared set of properties can be termed the "essence" of a natural kind; that "essence," in turn, must be "necessary, explanatory, and purely qualitative" (Sober, 1995). Natural kinds, moreover, constitute "a category of entities classically conceived as having modal implications; e.g., if Socrates is a member of the natural kind *human being,* then he is necessarily a human being" (Audi, 1995). For further discussion of natural kinds, especially in the context of disability, see Merriam, 2009 and Cooper, 2008.

[10] By 'non-epistemic' is meant any normative values that are *not* epistemic—so, for example, moral and aesthetic values, etc. Some specific examples of "nonepistemic goals" or values include "the relief of pain, the preservation of function, the achievement of desirable human form and grace, and the postponement of death" (Engelhardt, 1996, p. 203). Epistemic values, by contrast, have to do with the goals involved in knowing truly: are given propositions true or false? justified or unjustified? warranted or unwarranted? certain/probable or uncertain/improbable? and so forth. More generally, the category of "epistemic values" also encompasses positions regarding the appropriate epistemic standpoint from which to render various evaluative judgments, e.g., judgments regarding "quality of life"—and, in particular, whether certain epistemic perspectives ought to be privileged over others, and if so, in what circumstances. For further discussion of these issues, see Chapter 5.

[11] This view does not exclude the possibility that instrumental values may *also* come into play; the claim is only that at least *some* non-instrumental (i.e., natural) values enter into determinations of health and disease.

a *normativist* of a *naturalist* variety. In this work, I advance this sort of position vis-à-vis the concepts of health and disease, and by extension, notions of disability as well.[12]

Due to a variety of problems with the neutralist position, to be discussed in greater detail in chapter 4 (in connection with the "neutral variation" view of disability), many philosophers of medicine have felt compelled to embrace some form of normativism vis-à-vis disease concepts. Engelhardt, for example, characterizes "disease" as a conceptual apparatus that enables one, among other things, to create a treatment warrant: medicine is, on this view, fundamentally concerned with *treatment* of "clinical problems," or conditions that are considered to be undesirable for one reason or another. Such treatment warrants are devised against the backdrop of ideals of form and function, freedom from pain, and desired life span. Medical language—encompassing concepts of disease, illness, disability, and so forth—has four distinct but interrelated functions. First, medical language is evaluative: terming a condition a "disease" is to render a negative judgment. Second, medical language is descriptive: seeing is always "seeing as," and we thus "see" diseases within a framework of descriptive expectations. Similarly, disease language is explanatory, serving to place a disease within a web of causal explanations. Finally, disease language is social performative: to pronounce someone "diseased" or "ill" is to place that person within a matrix of social expectations and, potentially, to burden that individual as well (e.g., with stigmatization). The upshot: determinations of health and disease have a wide array of evaluative components (Engelhardt, 1996, pp. 189-238; cf. Engelhardt, 2009).

The foregoing conceptual geography provides us with the resources to argue that disputes concerning the proper characterization of disease and illness, on the one hand, and disability on the other, exhibit a parallel structure. The issues in each case are nearly identical. For example, in the case of disease, one asks the questions: are diseases natural kinds? If so,

---

[12] This represents a sort of broadly Aristotelian/Thomistic approach to these issues, according to which (1) diseases (and, by extension, disabilities) are akin to natural kinds, at least in the sense that they are not *mere* instrumental classifications, (2) there *is* an ingression of non-epistemic (moral, aesthetic, etc.) values into determinations of disease, disability, etc., but (3) those values occur naturally, that is, they are not *merely* instrumental classifications. A consequence of this view (to take one example) would be that it would imply that the human *telos* includes being able to hear. Thus, to attempt *intentionally* to bring a child into the world *with deafness* (e.g., by means of genetic engineering) would be, in some sense, perverse—it would be to contradict the human *telos*. (This is not to say, of course, that there might not be good reasons for refusing "treatment" of deafness—e.g., implantation of cochlear implants—for *already existing* deaf persons. For more on some of the pros and cons of cochlear implants, particularly from a medical point of view, see Papsin & Gordon, 2007). For discussion of some of the ethical issues involved in intentionally bringing deaf children into the world, see Merriam (2009).

how does one pick out and individuate them? Likewise, when we seek to understand the nature of disability, we can ask the questions: are disabilities natural kinds? If so, how do we pick out and individuate them? Moreover, as with disease language generally, "disability" language also can be seen to have evaluative, descriptive, explanatory, and social performative force. Just as "disease" determinations carry with them potentially profound social implications, so, too, do "disability" judgments.

B. On The Analogy Between 'Disease' And 'Disability'

The obvious next step in our larger argument is to establish the analogy between "disease" and "disability" upon which the above argument rests. To that task we now turn. Before proceeding, however, it must be emphasized that the claim here is not that disease and disability are *identical* or analogous *in all respects*; rather, the claim is they are analogous in certain relevant respects, such that certain things we can say about one can also be said about the other. There is, in particular, one key respect in which the notions of disease and disability are analogous—namely, the *language* used to speak about each of them.

We saw earlier that disease language is (a) evaluative, (b) descriptive, (c) explanatory, and (d) social performative. If the analogy between disease and disability is correct, then we should expect to see the same four functions in "disability" language as we see in "disease" language (and other medical language) more generally. To that end, consider the following ways in which disease and disability language parallel one another in being evaluative, descriptive, explanatory, and social performative, respectively.[13]

1. Disease and disability language as *evaluative.*

As Engelhardt (1996, pp. 203-204) explains, to call something a "medical problem" is to make a value judgment concerning it, i.e. to "disvalue" or place a negative value on it. Thus, to call a person diseased (ill, deformed, disabled, etc.) is to render an "adverse judgment" (pp. 203-204). To be deemed "diseased" is a negative evaluative judgment—all other things being equal,

[13] As we saw in the case of "disease" language, while there is overlap between these four aspects of "disability" language, nevertheless they can be distinguished logically; cf. Engelhardt, 1996, p. 196.

people do not want to be diseased, they will seek to avoid being diseased, and they will seek treatment and/or cure once found to be diseased.[14]

---

[14] What is it that *makes* disease bad? What is the *source* of the values involved in declaring a given state to be one of disease? Are the relevant values to be found in nature—that is, can they simply be "read off" of nature, without the intrusion of any further normative notions? Can the relevant values be discerned in the products of evolutionary processes? Or do they come from elsewhere? Engelhardt (1996) considers each of these possibilities in turn, arguing to the conclusion that the values in question must come from sources other than nature itself and/or the products of evolution.

One might begin by searching for values in "in nature." That is, one might look to nature itself to disclose a "canonical" standard for "normality" or "species design," particular departures from which would then count as "disease" entities. The problem with this, however, is that apart from a theological or other context, it is difficult if not impossible to discern such a "canonical" standard simply by looking at nature itself. As a case in point, consider color blindness: is color blindness a defect or advantage? The answer to this question depends not only on the context (e.g., being able to detect camouflage), but also on whether or not one takes there to be a normative standard against which the species (in this case, human beings) ought to be measured (Engelhardt, 1996, p. 198). The difficulty, in other words, is that one must *presuppose* the existence of such a "normative standard" before one can answer the question about color blindness. Simply "looking at" nature will not, by itself, provide an answer to that query. Similarly, Engelhardt argues, it will be difficult to discern, simply by looking at nature, what should count as "natural" or "unnatural" acts. What constitutes the "natural" or "proper" function of the human body? How can one be sure that certain acts are "unnatural"? In this regard, Engelhardt asks,

> [h]ow does one discover the norm from which the activities deviate? Does one appeal to statistical frequencies regarding what individuals usually or customarily do in a particular society? If so, what moral force would such findings have? How would they disclose a biological or physiological ideal? (Engelhardt, 1996, p. 197).

After all, as Engelhardt points out, "[f]rom the fact that most people may lie or cheat to some extent, it does not follow that such behavior is praiseworthy, proper, or ideal" (Engelhardt, 1996, p. 198).

Perhaps, one might suggest, one can answer these questions apart from a theological or other such context, by looking to the products of evolution. Here, the idea would be that characteristics that are "species-typical"—that is, have come about as a result of evolutionary processes—will count as "normal species design," and "species-atypicality" will count as "disease" entities. This is the approach taken most famously by Christopher Boorse. However, there are, according to Engelhardt's analysis, at least five key problems with such an approach. First, it fails to distinguish between "individual reproductive fitness" and "inclusive fitness." From an evolutionary standpoint, "[w]hat appears to be important... is not whether a particular individual reproduces, but whether that individual maximizes the chances of his genes being spread in the gene pool" (Engelhardt, 1996, p. 200). Consequently (to borrow Engelhardt's illustration), a "bachelor male" who remains unmarried and stays at home with his siblings might in fact increase his *siblings'* reproductive chances, thereby maximizing the overall likelihood that genes like his are passed on in the gene pool (Engelhardt, 1996, p. 200). Moreover, "typicality" can encompass a multiplicity of "designs" and "traits"—that is, "a balance among various contrasting traits," or balanced polymorphism, in which overall "inclusive fitness" may be achieved, but at the cost of "individual (reproductive) fitness." In other words, "[t]here may not be a single design, but rather a number of designs," a balance among which is itself conducive to the inclusive fitness of the species (Engelhardt, 1996, p. 200). For example, sickle cell disease simultaneously has the effect of reducing the individual reproductive fitness of the person who bears the condition, while also increasing the overall inclusive fitness of the human species (by conferring on pregnant women protection against fulciparium malaria). From an evolutionary standpoint, while this consequence may be unfortunate for the individual stricken with sickle cell disease, it can nonetheless be seen as a "success" of the evolutionary process. So what, then, should count as a "species-typical" blood type for human beings? Apparently, the "species-typical" blood type for human beings encompasses "a balance among types that may include sickle cell" (Engelhardt, 1996, p. 200). And if that is the case, then "[t]he 'human species typical design' appears to be a balance among a number of different designs or traits" (Engelhardt, 1996, p. 200).

Second, identifying a "medical problem" requires a prior specification of the relevant *environment* and *goals* (Engelhardt, 1996, p. 201). For example, should sickle cell trait be considered a *disease*? The answer to this question will turn on whether one is adopting an "individual-oriented" or a "species-oriented" normative standpoint. From the perspective of the individual—for whom the pain, suffering, and limitation of life expectancy caused by sickle cell trait will call out for medical treatment—it will make sense to label the condition a disease. By contrast, if one is concerned to maximize the overall inclusive fitness of the human species, one will be reluctant to view the trait as a disease, and will in fact desire that the trait remain in the gene pool, as protection against the possibility that, "through some worldwide catastrophe," fulciparium malaria were to spread uncontrollably (Engelhardt, 1996, p. 201). Similarly, in order to be able to determine whether or not an individual is "well adapted," one must first specify both an environment and a set of goals. This is because there is a dynamic interplay between environments and goals, such that the requisites for satisfying various goals will change from environment to environment. Thus, for example, a fair-skinned Scandinavian "with lightly pigmented skin and without adequate clothing and protection from the sun" would be at significantly higher risk of developing skin cancer if she were suddenly to be "transported" to a tropical environment; by contrast, a dark-skinned equatorial resident, with highly-pigmented skin, would be at increased risk of developing conditions such as rickets if he were suddenly transported to a northern clime where exogenous vitamin D was scarce. In either case, even if one is adopting an "individual-oriented" perspective, one still cannot determine whether a condition counts as a "medical problem" unless one also specifies a relevant environment and set of goals. Ultimately, "appeals to evolution, reproductive fitness, and inclusive fitness do not resolve what should count as a problem to be treated by medicine"; rather, "[t]he

Moving now to the notion of disability, we note that disability is generally considered a "negative" diagnosis, one that can result in various actions intended to avoid the condition. In the prenatal context, this can include the practice of "selective termination," which for certain diagnoses is employed at a very high frequency. For example, the British National Health Service

---

notion of successful adaptation is context specific and determined by what one wishes to achieve in a particular context" (Engelhardt, 1996, p. 201).

Third, such an approach fails to appreciate the distinction between *past* and *present* adaptations to environments. The point here is that, as far as evolution is concerned,

> we are the product of blind, selective forces which, if they have been successful, have adapted us to environments in which we may no longer live. Since what is species typical may represent an adaptation to environments in which we no longer live, it may not afford us the same degree of adaptation as that provided by some species-atypical trait (Engelhardt, 1996, p. 201).

Moreover, as an impersonal process involving "blind, selective forces," evolution itself cares nothing about the comforts, pleasures, or goals of individual human beings. Consequently, one will not be able simply to look at the products of evolution in order to determine what should count as a "medical problem." Instead, "[c]onditions stand out as problems because they thwart the goals of particular individuals or groups of individuals or because they make difficult the realization of particular understandings of the good or virtuous life" (Engelhardt, 1996, p. 202).

A fourth reason why such an approach will not work is related to the point made earlier, that determining whether or not a condition should count as a "medical problem" requires first specifying an environment and a set of goals. Here, the further difficulty is that there can be a conflict between "the outcomes of evolution," on the one hand, and both "individual and societal goals and values," on the other (Engelhardt, 1996 , p. 2020). Sickle cell anemia once again serves as a paradigm example of this. From the perspective of evolution, the possession of sickle cell trait will be deemed a "success" of the evolutionary process; indeed, "[t]o speak metaphorically, the individuals who die of sickle cell disease are, from an 'evolutionary perspective,' sacrificed in the process of maximizing" inclusive fitness of the human species. By contrast, individuals afflicted with sickle cell anemia "will be concerned that their physicians treat them, not to maximize the survival potential of their genes or their species, but to achieve the goals of relief and suffering and avoidance of disability, which the patients hold to be proper" (Engelhardt, 1996, 202).

Fifth, and finally, appealing to "nature" (evolution, etc.), renders one's judgments regarding "medical problems" subject to what has happened in the past; however, the "selective pressures" of nature can produce effects that range from being beneficial to neutral to downright harmful—so merely appealing to the results of evolutionary development will not yield an adequate account of species typicality or of disease more generally. Indeed, "[w]hat one now finds as species-typical levels of species-typical functions are the result of past selective pressures, which may have delivered biological capacities ill adapted to current circumstances" (Engelhardt, 1996, p. 202). For example, as a consequence of menopause, osteoporosis is (presently) a species-typical trait for post-menopausal women. Evolutionarily speaking, menopause "is most likely the result of past evolutionary forces in circumstances in which few women lived to reach menopause," as a consequence of which it "may have conferred neither advantage nor disadvantage" (Engelhardt, 1996, p. 202). Despite the fact that menopause is a product of evolutionary forces, however, most would consider osteoporosis—despite its "species-typicality"—to be a disease worthy of medical treatment. The point here, as Engelhardt puts it, is that

> [o]ne must recognize that the blind outcomes of nature are sometimes beneficial, sometimes, neutral, and sometimes undermining of our purposes and welfare. As a consequence, a physician will be unable to determine a classification of disease simply by attempting to discover what will count as species-atypical levels of species-typical functions. (Engelhardt, 1996, p. 203)

Given these considerations, Engelhardt concludes that having a species-atypical level of a species-typical function "is neither a necessary nor a sufficient condition for having a disease" (Engelhardt, 1996, p. 203).

So if the values implicit in labeling states of affairs as 'disease' do not arise straightforwardly from nature and/or the products of evolution, where *do* they come from? On Engelhardt's account, they arise as a result of a complex interplay among a variety of pragmatic, "nonmoral," and "nonepistemic" concerns. Central "nonepistemic" concerns include "the relief of pain, the preservation of function, the achievement of desirable human form and grace, and the postponement of death" (Engelhardt, 1996, p. 203). Relevant "nonmoral" concerns include "ideals of freedom from pain, of human ability, and of bodily form and movement" (Engelhardt, 1996, p. 206). From a pragmatic standpoint, "[s]ince the treatment of diseases is a societal undertaking, those conditions more generally acknowledged as problems worthy of treatment will be more easily accepted as diseases" (p. 205). In this regard,

> [o]ne encounters a wide range of problems that lie along a continuum. On one end of the continuum there are circumstances likely to be disvalued in whatever culture an individual lives, and in terms of whatever goals are possessed by individuals or societies. [On the other end] notions of proper human form and grace are heavily infected by values and cultural expectations (Engelhardt, 1996, p. 204)

For Engelhardt, the foregoing supports an anti-essentialist (or "nominalist," or "instrumentalist") view of disease, according to which

> [o]ne draws a line between innocent physiological or psychological findings and pathological findings because of particular human values in a particular circumstance, not because of the discovery of an essential distinction that exists outside of particular human expectations. In determining what should count as a problem warranting therapy, considerations of cost of treatment, quality of outcome, and length of survival may all be incorporated (Engelhardt, 1996, p. 205).

reported that from the years 1989 to 1995, 92% of fetuses diagnosed with Down Syndrome were aborted (NDAD, 1996, cited in Asch & Wasserman, 2006, p. 179). In a study of attitudes toward pregnancy among Israeli women compared with attitudes among Japanese women, Ivri Tsipy found that

> [t]he assumption that a woman seeking prenatal care intends to keep her pregnancy [as in Japan] does not hold true for the Israeli experience. Israeli pregnancies, Ivry argues, are understood through the lens of 'geneticism,' whereby the random assemblage of genetic material is the dominant factor in determining pregnancy outcome. The role of the Israeli mother is to try and determine the fetus's genetic makeup through a battery of prenatal diagnostic tests, and then to act according to the information she receives. Prenatal diagnosis is both widespread and aggressive, and in the event of an 'abnormal' diagnosis, abortion is expected (Evans, 2010, p. 12, citing Tsipy, 2009).

Moreover, the routine practice of prenatal diagnosis coupled with an "abortion presumption" for "abnormal" diagnosis appears to have embedded within it, in the Israeli context, a specific evaluative assumption regarding the life prospects faced by individuals with disabilities and/or their parents or other immediate family members:

> When pregnant Israeli women contemplate amniocentesis, a diagnostic test that can identify chromosomal abnormalities but carries with it the risk of miscarriage, Israeli ob/gyns routinely frame the decision thus, Ivry tells us: women must weigh the grief of losing a healthy child against the grief of bearing a child with a disability. Nowhere is the grief over losing a disabled child so much as even mentioned; it is taken for granted that a disabled child is unwanted. As for the disabled community in Israel, Ivry notes that "Israelis with disabilities are often quoted in the media as supporting the diagnostic endeavor to prevent the birth of other people who would suffer the kind of life that they endure" (Evans, 2010, p. 12, quoting Tsipy, 2009).

It should be emphasized that the point in this present context is not to condemn these practices from an ethical standpoint—that would be a different project entirely. Rather, for present purposes the point is to illustrate some of the ways in which the diagnosis of "disability" can have profound

evaluative force, which can issue in definitive "social performative" consequences as well (see below).

2. Disease and disability language as *descriptive.*

The basic idea here is that all descriptions of reality inevitably presuppose certain assumptions and expectations about the nature of explanation and evaluation. As Engelhardt puts it, "[d]escribing reality is always infected with both evaluative and explanatory expectations. One sees in terms of the interpretations one has in mind.... one sees reality already in terms of one's expectations..." (1996, p. 208). Consequently, "[t]he very description of findings as medical casts them in terms of explanations, often importing unnoticed the influence of values and theories." For example, should one see a shadow in an X-ray of a lung *as* pneumonia? Similarly, should one describe rapid breathing *as* "dyspnea" or "shortness of breath"? Adopting "medical" descriptions such as these constitutes a "diagnostic data transformation," and illustrates the reality that all seeing is "seeing as." What this means in the context of medical practice is that

> even to see problems as medical problems is to put them in a context rich with expectations and presumptions. Descriptions require standardization of terms. Such standardizations will be fashioned through quasi-political or societal discussions and against background assumptions about what will be useful in achieving particular goals and purposes. Those assumptions are themselves structured by explanatory views (Engelhardt, 1996, p. 208).

Arguably, the same sorts of claims can be made vis-à-vis disability—that is, to "see" disability "as" a medical problem is to place it within a context of certain expectations (e.g., a "disability role" analogous to the "sick role") and presumptions (e.g., disability is tantamount to weakness, invalidity, and/or tragedy). Indeed, this is one of the principal charges leveled against the medical model by advocates of the social model—namely, that by seeing disability "as," for example, tantamount to weakness, invalidity, or tragedy, one places it within a context of expectations and presumptions that can all too easily lead to stigmatization, unwarranted discrimination, condescension, and the like. Of course, one might also make the same sort of point about the social model approach, too—that is, seeing disability "as" social oppression *also*

places it within a context of certain expectations and/or presumptions (e.g., social justice claims of disabled persons against the broader society). Here again, the point for present purposes is not to adjudicate these potentially conflicting claims, but rather to highlight the reality that, just as with disease, to view a circumstance *as* disability is already to place it within a web of descriptive (as well as evaluative) expectations and presumptions.

3. Disease and disability language as *explanatory.*

In medicine, as in other sciences, observations are correlated and given coherence by way of explanation in order (a) to manipulate reality, and (b) to predict the future—i.e., to develop prognoses. However, these goals are pursued not strictly for their own sake, as they might be in certain "unapplied" sciences, but rather "in order to come to terms with the human pains, anxieties, disabilities, and deformities associated with clinical problems" (Engelhardt, 1996, p. 210). The nature of medical explanation underwent a radical change in the 19th century, during which time the findings of clinicians were correlated with and related to the findings of pathoanatomists and pathophysiologists. "Diseases" were now seen in terms of changes (lesions) at the organic level, rather than being defined by their clinical manifestations, as had been the case previously (see Engelhardt, 1996, Ch. 5, for a historical overview). As a consequence, the world of the clinic was restructured in terms of the world of the work performed in the laboratory and the dissection room.

Importantly, there is a "dialectical interplay between the descriptions of diseases and the explanatory models used in accounting for them" (Engelhardt, 1996, p. 210). The greater the reductive character of the description (e.g., at the cellular rather than the systemic level), the more likely it is that a patient's subjective experiences (aches, pains, sufferings, etc.) are to be discounted and/or ignored altogether. Alternatively, to the extent that the subjective experiences of patients *are* taken into account, to that extent such experiences will provide warrant for corresponding social roles. In this way, then, the language with which medical problems are described serves also to prescribe accompanying social roles, responsibilities, and the like. That is to say, "[b]y deciding whether a symptom is bona fide or *male fide,* medicine authenticates an

individual's claim to particular forms of treatment and a particular social role" (Engelhardt, 1996, pp. 216-217). [15]

This "authentication" role—as well as the more general explanatory functions of manipulating reality and predicting the future—is seen clearly in those cases in which physicians serve as "gate-keepers" for various social welfare or assistance programs, such as the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs. Indeed, for SSI/SSDI, being unable to work *because of* disability—as determined by a physician—is a fundamental eligibility criterion. Moreover, the eligibility criteria typically require some sort of concrete medical (i.e., biological/anatomical/physiological) diagnosis underlying any subjective experience that the individual might have of "being disabled" (e.g., by society)—once again casting disability in "medical" terms. Further, the physician's role as gate-keeper requires her to prognosticate regarding the *future* work capacity of the individual in question: "X will be unable to work for Y amount of time..."). [16]

4. Disease and disability language as *social performative.*

Medical diagnosis—for example, that which comes about as a result of genetic testing—shapes social reality by functioning as a source of social labeling. The very act of evaluating, describing, and explaining a cluster of phenomena as a "medical problem" simultaneously serves to place the sufferer of that "problem" in a particular social role—specifically, the "sick role," which Talcott Parsons famously described as being characterized by four key features, namely (1) a lack of responsibility for *being* in state of illness (though causal blame may remain for *contributing* to state of illness, e.g., through chronic smoking); (2) exemption from normal social duties; (3) a "therapeutic imperative"—i.e., a duty to seek out appropriate treatment from qualified individuals; and (4) a "defeasible assumption that sick people want to be treated" (Engelhardt, 1996, p. 217).

---

[15] The reader will recall from our discussion, in Chapter 1, of the Verbrugge/Jette (1994) model of disability, that for Verbrugge and Jette,

> [i]mpairments are identified via medical procedures, including exams, laboratory tests, imaging, and the patient's medical histories and reports of symptoms. This latter method is an extension of their original concept of the necessity of a diagnosis as a precondition for pathology. As in the first WHO model, this emphasis on diagnosis or 'exteriorizaiton' implies a need for legitimation from the medical profession.... From this perspective, self-reports are questionable and effects from new conditions, such as chronic fatigue syndrome, fibromyalgia, or Gulf War syndrome, are invalid until such conditions are identified and accepted by the medical system (Altman, 2001, pp. 104-105).

[16] "For SSDI and SSI, the evidence must show that a person has an impairment expected to last a year or result in death. Because of this impairment, a person must be unable to engage in substantial gainful activity measured by a dollar amount which is presently $940 [per month]" (Owens & Cassell, 2009, p. 201).

The respective social expectations—for the patient, health care professionals, insurance companies, society as a whole, etc.—will vary, depending on both the diagnosis and the therapeutic goals (Engelhardt, 1996, p. 217ff.). As with disease, being deemed "disabled" can have profound social performative effects, including rendering one either eligible or ineligible for various social benefits, as well as potentially casting one into what might be termed a "disability role." For a bit of historical background on the first of these effects, we turn to Silvers (2003).

a. Eligible/ineligible for benefits

According to Silvers (2003), the historical development of the contemporary notion of "disability" can be traced back at least as far as the 19th century, where disability was understood primarily in conventional and legal terms, as marking off a set of abilities (e.g., voting) from which a given set of individuals (e.g., women) was legally excluded—hence, for example, women were legally "disabled" from being able to vote. Over time, "disability" was imported into medicine, where it took on a "medical meaning" according to which "disability" was taken to refer to "natural limitations imposed by illness or accident" (Silvers, 2003, p. 472). Finally, the term made its way back into the legal context, where it is now performs a "gatekeeping" role (with physicians functioning as the "gatekeepers"), for such purposes as determining eligibility for supplemental disability income and other government assistance programs.

The move toward this notion of disability, in which "disability" refers to "physical, sensory and mental limitations," was prompted by the need for

> a terminology to refer to groups of individuals who, despite very different kinds of limitations, had been made eligible by statute for various kinds of benefits, such as compensation because their limitations resulted from injury during military service or justified their exclusion from the workplace (Silvers, 2009, pp. 24-25).

This "extended application" of "disability" had the effect, in turn, of placing physicians in a "gate-keeping" role, whereby they were asked not only to diagnose medical conditions but also to determine the extent to which such conditions would be "limiting" in the context of the workplace, "despite their lack of expertise about all the ways to accomplish different kinds of work" (Silvers, 2009, p. 25).

Clinical definitions of disability thus are frequently employed for purposes of determining eligibility for benefits, such as rehabilitation, education, and welfare programs, where medical practitioners (particularly physicians) take on a "gate-keeper" role or function. The focus of clinical definitions tends to be on pathological conditions: "[c]linical definitions are associated with the pathology that medical practitioners identify within the individual and the prognosis that the practitioner expects relative to the type of condition and the characteristics of the patient" (Altman, 2001, p. 99-100). In the hands of medical practitioners, then, clinical definitions take on a social performative force:

> Clinical definitions have their basis in the authority that is attached to medicine and carried out by medical specialists. As such, the clinical category, as named and documented by the medical provider, becomes the label and legitimization required to qualify a patient for rehabilitation, education, or welfare programs (Altman, 2001, pp. 99-100).

An example of this sort of definition of disability would be those put forth in the *Guides* developed by the American Medical Association's Committee on the Rating of Mental and Physical and Impairment (Altman, 2001, p. 100; cf. AMA Committee on Medical Rating of Physical Impairment, 1958).

Administrative definitions of disability have a similar social performative force. Today, as Owens and Cassell (2009) explain,

> [p]erhaps the most prominent societal response to working aged persons with disability is payment of compensation in lieu of wages. (Over $50 billion in disability compensation of one type or another is paid per year.) To receive disability compensation, persons must fit into administrative disability categories based for the most part on loss of earnings and severity of medical conditions (2009, pp. 199-200).

This, of course, raises a number of important conceptual and practical issues, including (among others) (1) "[e]stablishing legitimate categories for publicly funded compensation in lieu of wages," and (2) "[a]ddressing [the] concern[s] of citizens about the cost and potential for misuse of publicly funded programs" (Owens & Cassell, 2009, p. 200).

With respect to the first of these concerns, Owens and Cassell discuss the ways in which norms of social justice—in particular, norms regarding the relationship between individual contribution ("work") and the just distribution of wealth and resources—enter into the development and application of such administrative categories. In this regard, they observe,

> [s]ocial justice is made evident in the identification of legitimate categories for exclusion from a society's expected norms. In western societies individuals of a certain age are expected to work and support themselves as a condition of receiving their just share of wealth and resources. Disability is generally considered a legitimate category that justifies not working and qualifying for compensation in lieu of work. "Each category must be based on a culturally legitimate rationale for nonparticipation in the labor system…. The definitions are also tied to underlying cultural notions about work" (Stone, 1984, p. 22). The Social Security Disability Insurance (SSDI) and Supplemental Security Income for the Disabled (SSI) programs use rule-based categories to provide disability compensation to persons who cannot work because of a medical impairment. These rules include a carefully constructed assessment process, medical documentation of a physical or mental medical condition, and an administrative rating of impairment severity and work capacity. For SSDI and SSI, the evidence must show that a person has an impairment expected to last a year or result in death. Because of this impairment, a person must be unable to engage in substantial gainful activity measured by a dollar amount which is presently $940 [per month] (see *socialsecurity.gov* website). For SSDI, people who work pay into a fund to protect themselves against work disability and that fund pays if they meet the definition. SSI is a needs-based program where society pays the cost through general revenue when persons meet the disability definition and also meet income and resource limits (Owens & Cassell, 2009, p. 201).

With regard to the second issue—namely, the worry about the potential for abuse of the "disability" category—Owens and Cassell note that

> [w]hile western societies overwhelmingly accept disability compensation as a part of responsible social justice principles, there are concerns regarding overuse or misuse of

> the disability exemption to work (the moral hazard issue). There are also strongly and widely held views that many persons who fit categorical definitions of disability can work given adequate incentives and support. Therefore, they retain a responsibility to work, should be encouraged and supported in work efforts, and should not be discriminated against in the workplace. Economists worry that persons with disabilities who can satisfy their needs through disability compensation may not be motivated to enter the labor market, especially in view of other environmental and employment barriers.... Fears of deception, abuse, symptom exaggeration or malingering have generated vigorous tactics to discover and deal with abuses in both public and private programs... (Owens & Cassell, 2009, pp. 202-203).

Importantly, compensation in lieu of work is embedded in the context of a larger, overarching value or goal—namely, that of enhancing the social participation of persons with disabilities. As Owens and Cassell explain,

> [i]ncreasingly, compensation is seen as only one part of a social justice system to increase participation of persons with disabilities. At the same time, it continues to be accepted that for some persons with impairment, actual work activity is not possible. In those cases compensation may be the primary tool to allow for participation and increase quality of life....
>
> Participation in society—including the performance of apposite social roles, e.g. work—is now frequently cited as the most desirable outcome of social policy... (Owens & Cassell, 2009, p. 203).

Clearly, a diagnosis of disability carries with it a whole range of social implications. This social performative force of disability language, in turn, forces us to face directly the controversial question of whether or not it makes sense to speak of a "disability role," and if so, what that might mean. We turn now to that issue.

b. A "disability role"...?

As we noted in the Introduction to this work, Talcott Parsons argued that those whom medicine labels as "diseased" enter into, or take on, what he terms the "sick role." There is an

ongoing debate about whether or not those who are deemed "disabled" likewise adopt, or come to enact, an analogous "disability role." We will briefly consider this question here.

In an effort to get a handle on this question, and some of the implications that a given answer to it might have, it will be worth our while to engage with Michel Foucault's account of disease, as developed in his *The Birth of the Clinic* (1994/1963). Arguably, some of Foucault's insights in that work will be helpful to us in addressing the question of whether or not there is a "disability role" that is relevantly analogous to Parsons' "sick role." Moreover, Foucault's account provides us with some useful resources with which to extend and deepen our understanding of the nature of disability, particularly in relation to questions about the notion of a "disability role" specifically, and the "social performative" force of the 'disability' designation more generally. To that end, we begin with a brief overview of Foucault's account of disease, followed by a sketch of how that account might be extended fruitfully to the concept of disability.

(1) Brief overview of Foucault's account of disease

Foucault (1994/1963) advances a framework in which "disease" is viewed from (or within) the perspective of three distinct but interrelated "spatializations." In the first spatialization, that of "nosography" (the systematic classification or description of diseases),[17] medical perception is characterized by the "clinical method." The role of the physician is that of a (pure) clinician, a passive observer of "symptoms," a taxonomer (or classifier) of essential disease entities. The epistemological foundation of such perception is those (pure) "clinical essences," defined by constellations of symptoms, to which the physician directs his "medical gaze."

In the second spatialization, that of "pathoanatomy," medical perception is characterized by the anatomo-clinical method, in which the physician takes on a much more active interpretive role: namely, that of interpreting the "qualitative variations" of different diseases in the context of their organic localizations. Such "interpretation" is, at this level, carried out largely on the basis of the findings of laboratory tests and experiments—hence, in this second spatialization, the constellations of symptoms that characterize the first spatialization are now *explained* in terms of

[17] 'Nosography' is defined by the *Merriam-Webster's Medical Dictionary* (2007) as "a description or classification of diseases." *The American Heritage Stedman's Medical Dictionary* (2002) defines the term as "[t]he systematic description of diseases."

the findings of the basic sciences (pathoanatomy, pathophysiology, etc.). Here, the epistemological foundation of perception is the empirical observations of laboratory data.

Finally, the third spatialization—that of sociopolitics—engages the first two in a dialectical relationship, investing the findings of the clinic and the laboratory with social significance and import. At this level of spatialization, the physician literally becomes a constructor of social reality: a diagnosis of "disease," for example, can carry with it profound social implications, involving (among other things) the performance of a "sick role" by the patient, which can involve the exemption of the "diseased" person from normal social duties and obligations; the quarantining of persons with infectious diseases; and so forth.

To summarize: "disease," on the Foucauldian model, can be viewed simultaneously from three interlocking perspectives—that of the clinic, that of the basic sciences, and that of the sociopolitical context, respectively. "Disease," at the end of the day, is not *merely* a cluster of symptoms, nor is it *merely* a set of laboratory findings, nor yet is it *only* a social construction—it is all these things at once. Another way of putting this is to say that there are, as it were, three different "levels" of explanation, each of which interacts with the others in various ways, each of which is individually necessary and (only) jointly sufficient for such an adequate account.

(2) Extending Foucault's account to disability

As it turns out, the Foucauldian approach to disease provides us with a useful heuristic framework for understanding the concept of disability. If we were to apply Foucault's system of "spatializations" to the concept of disability, the results might look something like this:

(1) In the first spatialization, that is, the clinical world of signs and symptoms, "disability" can be construed as a physiological or anatomical condition that interferes in some way with the functions and activities in which persons normally engage.

(2) In the second spatialization, "disability" is understood in terms of underlying pathological processes—e.g., cellular mutations and the like.

(3) In the third spatialization, "disability" takes on a sociopolitical cast, with implications for the individual that, arguably, are similar to that of the "sick role"—what might, by analogy, be called a "disability role." On the one hand, the determination that one is "disabled" can

> render one eligible for special privileges and benefits, such as reserved parking spaces, Medicaid, Supplemental Security Income, and the like. On the other hand, as many disability advocates have rightly pointed out, "disability" can also render one vulnerable to stigma, discrimination, stereotyping, a lack of opportunity and a lack of full inclusion in society.

Now, we need not defend each of these specific contentions at the moment. The salient point for present purposes is simply that the designation of "disability" appears to have a "social performative" force (cf. Engelhardt, 1996, ch. 5) that cannot be assimilated to either the world of the clinic—the "signs and symptoms" with which disability is associated—or the world of the basic sciences, where disability is viewed at the cellular and physiological levels. Given the social performative force of the "disabled" designation, it seem plausible to speak of a "disability role" that is, in at least certain respects, analogous to a "sick role."

The particular value of Foucault's account of disease here is in helping us to see more clearly the social-political dimension of the "disability" category. For example, just as there is a political question that must be resolved vis-à-vis financial reimbursement for treatment of disease, so, too, there are analogous political questions with respect to disability (who will pay for a new wheelchair or crutches for someone with a physical disability? who should shoulder the costs of long-term residential care for persons with intellectual disabilities? etc.) More generally, we can say that the "clinical symptoms" associated with disability parallel (roughly) Foucault's "first spatialization"; the medical model of disability parallels (roughly) the second spatialization (disability is explained in terms of underlying pathological physiological processes); and the social model of disability parallels (roughly) the third spatialization ("the disabled" are cast, sociopolitically, into a "disabled role," rendering them susceptible to certain responsibilities and potential burdens—including the potential for stigmatization—on the one hand, and also making them eligible for certain benefits, on the other).

Foucault's system of "spatializations," as applied to the concept of disability, thus provides us with a way of understanding how the different aspects of disability—symptoms, underlying medical conditions (pathological, etc.), and social-political—interact with each other.

Arguably, just as with disease, all three aspects are present in any given case of disability. If this is the case, then the social and medical models alike go wrong in attempting to reduce the nature of disability to *only* one component (medical, social, etc.).

***

Returning now to our larger project, the general moral to be drawn at this point is, again, that disability is relevantly analogous to disease, such that at least some of the things that can be said about the latter can also be said about the former. Specifically, just as 'disease' is evaluative, descriptive, explanatory, and social performative, so too is 'disability.' We will, therefore, proceed on the basis of that assumption, highlighting its significance at relevant points along the way.

V. ENGEL'S "BIOPSYCHOSOCIAL MODEL" OF DISEASE

We saw in chapter 2 that the three general approaches to modeling disability—"medical," "moral," and "social," respectively—will ultimately turn out to be inadequate, because each of them misses something important that ought to be captured by any adequate account of disability. As an alternative, we suggested there that a "biopsychosocial" approach to disability would be superior to the other options on offer. The burden of this chapter is to show that that is indeed the case, and why this is so. This part of chapter 3 launches us into that project by presenting an overview and analysis of George L. Engel's "biopsychosocial model of disease," which serves as the inspiration for this work's proposal of a modified BPS approach to disability. With this in mind, this portion of chapter 3 explicates Engel's "biopsychosocial model of disease," identifies key elements of that theory, and sketches how those elements might apply to an analysis of the concept of disability. This part of the chapter thus constitutes an argument to the conclusion that Engel's "biopsychosocial model" provides a useful framework within which to think about the nature of disability, and thereby serves to motivate the use of this approach in the context of this work's larger project of developing a comprehensive analysis of disability.

A. Explication of Engel's Approach

Some thirty years ago, in an article entitled "The Need for a New Medical Model: A Challenge for Biomedicine," George L. Engel (1981/1977), called upon his psychiatric colleagues (and, indeed, all medical professionals) to move beyond what he termed the "biomedical model"

in favor of an expanded, or "new" version of the "medical model,"[18] one that would encompass considerations of "biopsychosocial" factors—that is, biological, psychological, and social factors, all of which, on Engel's view, must be included in any adequate account of disease. Engel described the regnant "biomedical model" of the day in the following terms:

> The dominant model of disease today is biomedical, with molecular biology as its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biologic (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behavior, it also demands that behavioral aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes. Thus the biomedical model embraces both reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle, and mind-body dualism, the doctrine that separates the mental from the somatic. Here the reductionistic primary principle is physicalistic; that is, it assumes that the language of chemistry and physics will ultimately suffice to explain biological phenomena. From the reductionistic viewpoint, the only conceptual tools available to characterize and experimental tools to study biological systems are physical in nature (Engel, 1981, p. 591).

It is important to note that Engel is *not* advocating an abandonment of the "medical model" altogether; indeed, he acknowledges that the "biomedical approach" has brought with it a host of "enormous advantages" (Engel, 1981, p. 594).[19] Rather, he is arguing for a *revised,* expanded conception of that model, one that will include not only biological elements, but psychological and social ones as well. As Engel puts it, "[w]e are now faced with the necessity and the challenge to

---

[18] For roughly contemporaneous discussion of the "medical model," including its perceived virtues and vices, see Veatch, "The Medical Model: Its Nature and Problems" (1981). Veatch identifies the following as key characteristics of the medical model: (1) "non-voluntariness" (the individual is not diseased/ill voluntarily); (2) "organiticity" (i.e., a focus on organ-level symptoms and functions); (3) "the physician as the technically competent expert," and (4) "restoration of a minimal standard of health."

[19] As Engel puts it, "[t]he biomedical approach to disease has been successful beyond all expectations, but at a cost" (p. 594). Engel does not here elaborate what sorts of "successes" he has in mind, though presumably he has in mind something like the great advances in treatment and cure of conditions made possible by the modern "biomedical" model. He does elaborate, later in the same article, on some of the "costs" to which he here alludes.

broaden the approach to disease to include the psychosocial without sacrificing the enormous advantages of the biomedical approach" (Engel, 1981, p. 594).

According to Engel, all of medicine—including psychiatry—is in a state of "crisis." The source of this crisis is, on Engel's view, an uncritical adherence to an "inadequate" model of disease, the "biomedical model" of disease. This model, Engel says, is inadequate both for the "scientific task" and for the "social responsibilities" to which medical professionals are called.[20] The uncritical adherence to this model has led to a crisis both in psychiatry specifically—can "psychosocial problems" (e.g. depression) even be considered *diseases*?—and in medicine generally: if disease is understood strictly in somatic terms, then there would appear to be no need to be concerned about psychosocial issues whatsoever, a consequence that appears unpalatable at best.

The crisis in psychiatry has, on Engel's account, been answered in two different ways. On the one hand, an exclusionist position, represented by the likes of Szasz,[21] argues that psychiatry is simply not a part of medicine at all; hence, "psychosocial problems" do not fall under the purview of medicine. By contrast, a second position embraces the "medical model" of disease, but limits psychiatric problems to those behavioral problems that are "consequent to brain dysfunction." Thus, any "behavioral problems" that cannot be explicated in terms of underlying brain dysfunction or disorder are simply deemed not to be "psychiatric problems" (or diseases) in the first place. The important point, for Engel's purposes, is that both responses implicitly assume the conceptual adequacy of the medical model. The crucial question, then, is this: *is* the medical model adequate for psychiatry and/or medicine? Engel answers that question in the negative, arguing instead for a broadening of the medical model to include psyschosocial considerations.

This broadening of approach is necessary, Engel argues, because an exclusive focus on the biomedical, to the exclusion of the psychosocial, "distorts perspectives and even interferes with patient care" (1981, p. 595). Using diabetes (a seeming paragon of "somatic disease") and

---

[20] "'The doctor's task,' explained Engel to anyone who might have thought it consisted of making house calls or providing care, 'is to account for the dysphoria and the dysfunction which lead individuals to seek medical help, adopt the sick role, and accept the status of patient-hood'" (Shorter, 2000, p. 6, quoting Engel, 1977, at 129-132).

[21] Engel here cites Szasz's *The Myth of Mental Illness* (New York: Harper & Row, 1961).

schizophrenia (an apparent paradigm of "mental disease") as illustrative examples, Engel argues that this "distortion" can occur in at least six ways.

First, the presence of a "biochemical defect" is a necessary but not sufficient condition for the experience of illness. That is, while the presence of a "biochemical deviation" is frequently a diagnostic marker for disease potential, its mere presence is not sufficient for the experience of illness at a given point in time. Illness is frequently a function of interaction between the biochemical defect and other factors that interact in complex ways. Moreover, understanding the phenomenological *experience* of illness[22] requires reference to features that go beyond the biochemical level. Thus,

> while the diagnosis of diabetes is first suggested by certain core clinical manifestations, for example, polyuria, polydipsia, polyphagia, and weight loss, and is then confirmed by laboratory documentation of relative insulin deficiency, how these are experienced and how they are reported by any one individual, and how they affect him, all require consideration of psychological, social, and cultural factors, not to mention other concurrent or complicating biological factors. Variability in the clinical expression of diabetes as well as of schizophrenia, and in the individual experience and expression of these illnesses, reflects as much these other elements as it does quantitative variations in the specific biochemical defect (Engel, 1981, p. 596).

In sum, an exclusive focus on "biochemical defect" fails to capture adequately the *experiential* dimensions of illness.[23]

Second, psychosocial concepts are needed in order to understand and explain adequately the correlation between laboratory and clinical data—that is, laboratory data often can be interpreted accurately only against the background of certain psychological and/or social concepts. Clinical phenomena are most frequently reported by individuals in terms of psychological and/or social concepts; hence, a "scientifically rational approach to behavioral and psychosocial data" is required. More specifically, "[a]n examination of the correlations between

---

[22] For a full-length treatment of the phenomenology of the illness experience, see Toombs (1992).

[23] It is worth noting that Engel moves back and forth between speaking of "disease" and "illness" without carefully distinguishing the two. However, for his purposes here—i.e., demonstrating that psychosocial factors are as relevant to disease and illness as are biological (biochemical, etc.) factors—it is not clear that he *needs* to distinguish sharply between the two in this context.

clinical and laboratory data requires not only reliable methods of clinical data collection, specifically high-level interviewing skills, but also basic understanding of the psychological, social, and cultural determinants of how patients communicate symptoms of disease" (Engel, 1981, p. 596). As an example, Engel points to the fact that many verbal expressions are phenomenologically rooted in bodily experiences that occur early in one's life, as a result of which there can be a considerable degree of ambiguity in the language that different persons use to report symptoms. Consequently, the same or similar linguistic terms may be used to report both "primary psychological... and bodily disturbances." Practically, this can make it difficult to distinguish between two conditions whose symptoms may be similarly reported, such as diabetes and schizophrenia. As Engel explains, "virtually each of the symptoms classically associated with diabetes may also be expressions of or reactions to psychological distress, just as ketoacidosis and hypoglycemia may induce psychiatric manifestations, including some considered characteristic of schizophrenia" (Engel, 1981, p. 596). Thus, Engel concludes, "[t]he most essential skills of the physician involve the ability to elicit accurately and then analyze correctly the patient's verbal account of the illness experience." The biomedical model, he says, "ignores both the rigor required to achieve reliability in the interview process and the necessity to analyze the meaning of the patient's report in psychological, social, and cultural as well as in anatomical, physiological, or biological terms" (Engel, 1981, p. 596).

Third, various "psychophysiological responses to life change" can affect the onset, severity, and course of disease, thus necessitating an appeal to psychological and/or social concepts. In the case of both diabetes and schizophrenia, psychosocial factors can interact with "somatic factors," including a preexisting genetic predisposition to diabetes or schizophrenia, to alter one's susceptibility to these conditions—and thereby influence the time of onset, the severity, and the progression of those conditions once they become manifest in a given individual. This illustrates well, according to Engel, the important role of "psychosocial variables in disease causation" (Engel, 1981, p. 596).

Fourth, psychosocial factors can affect the timing of when individuals attain "patienthood" status and/or when they accept the "sick role." That is, psychosocial factors play a key role in

determining when individuals who have a given "biochemical abnormality"—such as those abnormalities associated with diabetes and/or schizophrenia, respectively—come to be viewed, either by themselves or by others, as "sick," as well as whether or not, and when, they seek help from the health care system (and thereby become a "patient"). In short, "the biochemical defect may determine certain characteristics of the disease, but not necessarily the point in time when the person falls ill or accepts the sick role or the status of a patient" (Engel, 1981, p. 596-597).

Fifth, psychosocial factors can explain the oft-observed "discrepancies between correction of biological abnormalities and treatment outcomes." Frequently a patient is not restored to health even after a biochemical defect has been corrected or at least significantly alleviated; this fact, Engel insists, cries out for explanation. Factors other than the biochemical

> may combine to sustain patienthood even in the face of biochemical recovery. Conspicuously responsible for such discrepancies between correction of biological abnormalities and treatment outcome are psychological and social variables (Engel, 1981, p. 597).

Sixth, physician behavior and the physician-patient relationship affect therapeutic outcome; therefore, disease cannot be explained solely in biological terms. These "psychological effects" can occur at multiple levels. On the one hand, they can directly influence how an individual *experiences* the disease process; on the other hand, they can indirectly affect how an individual responds, at the biochemical level, to various psychosocial stimuli. For example, a diabetic's insulin requirements can vary depending on how she perceives her relationship with her physician. Similarly, if a physician is to influence his patient to modify her behavior in a way that is conducive to her health, he must have a good understanding of her psychological constitution as well as her biological makeup. All of this, Engel concludes, lies "outside the biomedical framework" (Engel, 1981, p. 597-598).

In addition to these distorting influences, Engel also argues that, in fact, it is not possible to understand adequately the causes of disease, nor to develop a "rational" strategy for planning health care, without taking into account factors that go beyond the merely biological: indeed, an adequate medical model "must also take into account the patient, the social context in which he

lives, and the complementary system devised by society to deal with the disruptive effects of illness, that is, the physician's role and the health care system" (Engel, 1981, p. 598). For this task, Engel argues, nothing less than a "biopsychosocial model" will suffice; in short, good medical care *requires* taking psychosocial factors into account (Engel, 1981, p. 598). Ultimately, "...the physician's professional knowledge and skills must span the social, psychological, and biological, for his decisions and actions on behalf of patients span all three" (Engel, 1981, p. 600).

B. Theoretical Analysis of the BPS Approach

Put most simply, the biopsychosocial model amounts to the claim that "...mental and social events influence and interact with biological events" (Malmgren, 2000, p. 36). The basic idea behind this "crude formulation" is that "[w]e are talking about the possibility of mental factors causing real peptic ulcers and high blood pressure, not 'only' pain, suffering, and a lower quality of life" (Malmgren, 2000, p. 37). Stated in such bare-bones form, however, this does little to distinguish the biopsychosocial model (BPS) from the biomedical model (BM), so it will be worth our while to linger briefly over the question of the relationship between the two.

The literature tends to frame the relationship between the BPS and the BM as being either one of *opposition* or of *extension.* The "contradictory view" (i.e., opposition) is nicely summed up in the following passage:

> A BPS approach is one that incorporates thoughts, beliefs, feelings, behaviors, and their social context and interactions with biological processes, in order to better understand and manage illness and disability. In contrast the biomedical approach is a more linear approach that assumes phenomena can be explained solely by biological processes (White, 2000, Ch. 14, p. 226).

Alternatively, as Peter White (2000, pp. xv-xvi) explains, one might argue along the following lines to the conclusion that the BPS is an *extension of* the BM. On the one hand, "[t]he biomedical approach or model assumes that ill-health and disability is directly caused by diseases and their pathological processes." The problem with this approach is that it fails to account adequately for many instances of "chronic ill health" and the disabilities frequently associated with such ill health. For example, one can have a disease without symptoms, and one can present with symptoms

despite the lack of any obvious underlying disease. (As an illustration of the former, White points to "high blood pressure caused by an unknown kidney disease"; he points to "chronic pain disorder" as an illustration of the latter.) The upshot of this lack of explanatory power is what White refers to as a "paradox": despite the obvious benefits brought about by the biomedical approach—as a consequence of which "we have never been as healthy or lived for as long as we now do"—we nevertheless "seem to have more concerns about our health and suffer from more chronic disability than ever before." In brief, the biomedical approach seems to leave out important dimensions of our experiences of illness, disease, and disability. By contrast, the "biopsychosocial approach," as White limns it, "incorporates thoughts, feelings, behaviour, their social context, and their interaction with both physiology and pathophysiology into its approach to ill-health and disability. Such an approach does not abandon the biomedical model but extends it" (White, 2000, p. xv). In this way, White says, the BPS approach carries out Engel's program of taking into account "the patient, the social context in which he lives, and... the physician role and the health care system" (White, 2000, p. xv, quoting Engel).

C. Evaluation of the BPS Approach

For Simon O. Wessley, as it was for Engel, it is an undeniable fact that the "biomedical model" has, for all its problems, been incredibly successful—in a word, it has "delivered." In the opening paragraphs to his "Foreword" to a volume considering Engel's biopsychosocial approach to disease and the prospects for a biopsychosocial *medicine* oriented around that approach, Wessley puts the point this way:

> The biomedical model... delivers. Old people with fading cognitive abilities used to be derided and ignored as senile. But as our knowledge of the neurobiology of Alzheimer's has been transformed, so has our care of sufferers, and at last there are genuine hopes for progress in treatment. Likewise, no amount of prayer, incantations, amulets, or spiritual devotion could make any impression on the scourge of the great infections, but immunization and antibiotics managed it. And, to use an example beloved of several of the contributors to this book, psychotherapy failed to cure peptic ulcers, but discovering and then eradicating *H. pylori* did the trick. Let there be no mistake—modern scientific

> medicine is, as the late Roy Porter wrote, for once without his tongue-in-cheek, the "greatest benefit of mankind" (Wessley, 2000, p. vii).

Nevertheless, Wessley goes on to say, in arguing that "we needed... better to integrate mind and body, and to include the social context of illness as well" (Wessley, 2000, p. ix), Engel correctly pointed to a fundamental inadequacy in an exclusive focus on the biomedical to the exclusion of the psychological and the social. Given mounting empirical evidence showing that "social differentials, both at work and home, are major determinants of disease outcome" (Wessley, 2000, p. x), it appears increasingly necessary to recognize, with Engel, that the world—including the world of medicine and medical explanation—is "more complex tha[n] we could imagine" (Wessley, 2000, p. xii). For example,

> [t]wo decades of research have shown beyond a reasonable doubt that when it comes to symptoms, mind and body are inexplicably intertwined—if you have a lot of 'physical' symptoms, you will almost invariably endorse similar levels of 'psychological symptoms', and vice versa (Wessley, 2000, p. xiii).

At the same time, Wessley cautions, it is important to keep in mind that "[m]edical care remains dualistic, perhaps more so than ever." In a great many instances, both patient and physician alike are comfortable exploring the psychosocial dimensions of illness and disease only on the prior assumption that there is, simultaneously, an underlying biological explanation available (at least in theory) for a given state of illness or disease. Thus, for example, patients are often fearful that their reports of pain will be explained away as being merely "psychological" or "psychosomatic"; hence, they are willing to consider and discuss the psychosocial only if a biological or biochemical explanation for the condition has already been put forth. Practically, then, "[i]n the clinic... we seem best able to tackle the social and psychological only when we have solved the physical first" (Wessley, 2000, p. xiv). The upshot of this, on Wessley's view, is that for all its promise, the BPS approach is limited at best. Engel, he says, "was right in theory, but wrong in practice": "It is an irony... that perhaps the best way to improve the psychological support for, and understanding of, patients with a range of illnesses, is not to try to combine the mind and body" (Wessley, 2000, p. xiv) It is worth noting, in passing, that these latter

observations would appear to suggest the need to *keep* the biomedical level of explanation in play in constructing our accounts of disease, illness, and disability, and thereby lend further support to the claim that we need a *biopsychosocial* approach to disability, rather than a strictly medical or social approach.

VI. A "BIOPSYCHOSOCIAL" THEORY OF DISABILITY? APPLYING ENGEL'S APPROACH

The principal task of the remainder of chapter 3 is to show how these sorts of considerations are relevant to the larger project of developing a comprehensive analysis of disability. This task will be accomplished by taking some of the insights of Engel's model and building on them to show how they might apply to an analysis of disability. Thus, for example, it may be that the presence of a "biochemical defect" of some sort (broadly construed) is a necessary condition for some forms of disability (recall the points made earlier about the variability of disability), yet not sufficient; moreover, the *experience* of disability in such cases clearly and obviously cannot be fully explained solely by appeal to the presence of a biochemical defect. It is likely that similar analogues can be drawn to each of the other six points of "distortion" noted above, though we will not attempt here to map a one-to-one correspondence between Engel's six points, on the one hand, and elements of a BPS approach to disability, on the other. Instead, we shall simply draw a "sketch" of what such an approach might look like, in light of Engel's approach to disease and insights gleaned from that approach.

A. What Might a BPS Approach to Disability Look Like?: An Initial Sketch

The biopsychosocial approach explicitly recognizes and draws attention to the different dimensions of disability—specifically, the *biological, psychological,* and *social* dimensions of the disability experience, respectively. As an illustration of what this might look like, consider von Korff's (2000) argument regarding the role of psychological states in causing "social role disability" among members of the primary care patient population.

Michael von Korff argues that "psychological states, in particular fear and depression, are potentially remediable causes of social role disability among primary care patients" (von Korff, 2000, p. 117). This can come about in a number of ways. Fear, anxiety, depression, and similar

states can impair "the highest order capacities including concentration, motivation, energy, and self-confidence" (von Korff, 2000, p. 118). In fact, according to von Korff, "[a] growing body of research shows that depressive illness is often a stronger predictor of social role disability than the severity of disease-related impairments among people with common chronic medical conditions" (von Korff, 2000, p. 119). Similarly, "fear-avoidance" beliefs, and their attendant behaviors, can actually *increase* the degree of intensity and/or duration of disability among persons with chronic low back pain (von Korff, 2000, pp. 120ff).[24] Finally, psychological states can undermine a person's "resilience" and/or their "ability to effectively utilize resources in the social environment" (von Korff, 2000, p. 119-120).[25]

In sum, there appears to be a dynamic relationship between physical disease and psychological illness, on the one hand, and disability on the other:

> On the one hand, chronic physical diseases and chronic pain conditions can be viewed as major stressors that can induce or exacerbate psychological illness, particularly among people with a prior history of psychological illness. On the other hand, depression and anxiety may amplify pain and chronic physical symptoms that contribute to increased disability. Depressive illness is also associated with adverse health risk behaviors such as smoking and obesity and infrequent exercise (von Korff, 2000, p. 119).

In this light, von Korff concludes, "[t]his perspective suggests that the debate about whether psychological illness causes physical disease or physical disease causes psychological illness may be missing the mark" (von Korff, 2000, p. 119).

The significance of this for our larger project is that it lends further support to our thesis that disability must be understood *biopsychosocially.* At the same time, however, our specific focus in particular cases will differ—in some cases, our focus may be on the "bio" component, in others the emphasis may be more on the "psycho" component, and in still other cases we may

---

[24] For example, avoiding the use of one's lower back muscles can increase the risk of further pain or injury.

[25] In making this latter point, von Korff is drawing on Jette's proposal that:
...determinants of disability be conceptualized using the epidemiological triad of *host* (resilience or vulnerability factors), *agent* (impairments initiating disability), and *environment* (social mediators of adaptive or maladaptive response to impairments). From this ecological perspective, psychological impairment, particularly among persons with co-morbid physical impairment, may be critically important because they reduce both host resilience and ability to effectively utilize resources in the social environment (von Korff, 2000, pp. 119-120; cf. Jette, 1997).

focus our attention primarily on the "social" component. In each case, the primary question will be an *instrumental* one, namely, which factor(s) is/are easier to treat or address—biological, psychological, or social? Since (as we have seen) there will *always* be an interplay of physical, mental, social, and other components involved in disease, illness, and disability, the *practical* question becomes which of these is more easily addressed in any given case.

We see here a similar pattern as in the grading and staging of cancer. As Engelhardt (1996, Ch. 5) explains, the staging and grading of cancers is in part a matter of prudential judgments having to do with what we are able to do about various conditions—that is, what conditions we are able to treat and/or cure, and the costs associated with different courses of treatment or non-treatment. Moreover, the classification of a condition as a "disease" or other state falling under the purview of "medicine" has potentially far reaching ethical, public policy, and social performative force. Indeed,

> [w]hat one classifies as a disease and how it is classified as a disease has an immediate impact on persons' lives and on society in general. In examining a Pap smear, a decision must be made regarding how many cells with deviant changes of what character must be present before the smear is read as indicating cancer. To be too liberal in classifying cells as cancerous will lead to unnecessary operations. To be too conservative in the classification will lead women to receiving treatment too late for successful cure. How in part one discovers and in part creates lines between cancerous, noncancerous, and precancerous findings is of considerable moment for individuals concerned to keep their bodies intact while avoiding cancer, and for societies interested in containing medical costs and maximizing benefits for their members. How one fashions such classifications will have implications for morbidity, mortality, and financial costs.

These are just some of the ways in which "medicine creates a socially accepted reality" (Engelhardt, 1996, pp. 194-195). For example, different systems for staging cancers lead to different levels of treatment; in this way, systems for staging cancers "reflect decisions made by communities of physicians regarding the most appropriate and useful ways to characterize an area of reality" (Engelhardt, 1996, pp. 194-195). Such decisions will involve an agreement "to see

and react to reality in a disciplined and coordinated fashion" (Engelhardt, 1996, pp. 194-195), and these decisions will, in turn, have far-reaching practical import for patients. For example, "[t]he difference between a stage I and a stage II cancer will be expressed in the differences between limited surgical procedures and more extensive interventions with chemotherapy and/or radiation along with a less optimal prognosis" (Engelhardt, 1996, pp. 194-195).

We saw elements of a "biopsychosocial" approach at various points in our earlier examination (Ch. 1) of some specific models of disability. In Nagi's model, for example, impairment ranges along a number of dimensions, depending on a variety of biological, psychological, and social factors. Such dimensions, which in turn can affect "the nature and degree of disability observed" (Nagi 1977, 1991, cited in Altman, 2001, p. 104), include the

> degree of visibility and disfigurement, stigma, the predictability of the underlying pathology, the prognosis and prospects for recovery or stabilization, threat to life, types and severity of limitations in function they impose and the point of onset in the life cycle (Nagi, 1991, p. 314, cited in Altman, 2001, p. 104).

Similarly, the patterns of behavior that come to be labeled "sickness" or "illness"— behaviors which are triggered by the perceived presence of pathology or disease—are shaped and influenced by a number of biopsychosocial factors, including

> (a) characteristics of the pathological condition, that is, type of condition, nature of onset—whether traumatic and unexpected or degenerative with early warnings in signs and symptoms, severity of the associated impairment, and potential for recovery and control; (b) definition of the situation by the afflicted and their reactions, which are greatly influenced by (c), the definition of the situation by others and especially the reactions and expectations of significant others (Nagi, 1965, pp. 102-103).

'Impairment' itself is defined, on Nagi's model, as "anatomical and/or physiological abnormalities and losses" (Nagi, 1965, pp. 101-102)—giving the term, as we argued in Chapter 1, a biological focus. 'Disability,' in turn, is defined by Nagi as "a pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations" (Nagi, 1965, p. 103). As with impairments, the patterns of behavior involved in disability are

> subject to three types of influence: (a) characteristics of impairments, degree of limitations imposed, and the potential for rehabilitation; (b) the individual's definition of the situation and his reactions, which sometimes compound the limitations and which are also largely influenced by (c), the definition of the situation by others, their reactions and expectations—especially the reactions of those who are significant in the lives of the afflicted (Nagi, 1965, p. 103).

Ultimately, disability "refers to social rather than to organismic functioning. It is an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment" (Nagi, 1991, p. 315). This emphasis on role interactions gives Nagi's 'disability' a social valence, and the three major influences referenced in the quotation above clearly involve a variety of biological, psychological, and social elements. In light of the foregoing, then, we can plausibly construe Nagi's 'impairment' as constituting the "bio" component of a biospychosocial approach, and 'disability' as constituting the "psychosocial" components of such an approach.

In similar fashion, the ICIDH (WHO, 1980, p. 14) explicitly introduces a distinction between "disturbances at the organ level"—i.e., impairments—and "disturbances at the level of the person," i.e. disabilities. Impairments are understood as "abnormalities" in body structure and appearance, or in organ system or function. Disabilities, by contrast, refer to the effects that impairments may have on the individual in terms of her performance and/or activity—hence, they are "person-level" disturbances. Finally, "handicaps" are understood as "disadvantages experienced by the individual" as a result of either impairments or disabilities. Here, impairments and/or disabilities interfere with the individual's ability to perform key "social roles." Once again, we see the involvement of a variety of biological, psychological, and social factors in this model—'impairments' constitute the "bio" component, while 'disabilities' or 'person-level disturbances' constitute the "psychosocial" components—as a consequence of which we can arguably construe the ICIDH as a sort of proto-biospychosocial approach to disability.

To put this in different but related terms, we are in effect developing an "interactionist" approach to disability, along the lines suggested by Shakespeare (2006). Shakespeare's

interactionist account of disability is based on a "critical realist" (2006, p. 54) perspective regarding impairment, according to which impairments are ontologically real and have significant impact in and of themselves on the personal experiences of those who have them. Disability is an "emergent" property (Shakespeare, 2006, p. 55, citing Williams, 1999, p. 810), one that arises out of the complex interplay between a variety of biophysiological, environmental/structural, and socio-cultural factors. On this account, disability is "relational" (Shakespeare, 2006, p. 57)—it involves the interaction of *both* intrinsic and extrinsic factors (Shakespeare, 2006, p. 55), and can thus be distinguished from the medical and the traditional social model approaches (2006, p. 56). As such, this account bears affinities to and is compatible with a number of other approaches, including the "medico-psycho-social" (Shakespeare, 2006, pp. 59-60) model developed in the World Health Organization's *ICF*. Such an interactionist approach, Shakespeare contends, has a number of advantages, including its ability (1) "to account for the range and diversity of disabling experiences," and (2) to illuminate "the different ways in which the situation of disabled people can be improved" (Shakespeare, 2006, pp. 60-62). On Shakespeare's account, the source of both of these explanatory advantages can ultimately be traced to the interactionist approach's explicit recognition of "the ubiquity of impairment," a reality which is neither "neutral" nor "always all-defining and terrible." Instead of viewing impairments in either of those two ways, it is preferable to see impairments as presenting a "predicament" (Shakespeare, 2006, p. 63) to which all human beings are, to some extent or another, at least potentially susceptible. These predicaments inevitably pose certain challenges and limitations, and are therefore not "neutral"; nevertheless, they are also amenable to a variety of methods of intervention and/or amelioration.

B. A Limitation of the BPS Approach to Disability

In appropriating Engel's biopsychosocial approach for purposes of understanding the nature of disability, we must be mindful of an important limitation of the BPS approach. That limitation is that Engel's BPS approach does not provide us with a specific answer to the normativist/non-normativist debate. This is because Engel was speaking primarily about *levels of explanation* (biological, psychological, social) rather than intending to answer the normativist/non-normativist question *per se*. For that reason, Engel's theory is not particularly helpful in

adjudicating, for example, the Boorse-Engelhardt debate regarding the question of normativity.[26] For Engel, the various factors (biological, psychological, social, etc.) that play a role in disease and illness may be either normative or non-normative. Hence, we cannot settle the normativist/non-normativist debate simply by appealing to Engel. Interestingly, however, this limitation might in fact be taken to be a *virtue* of appropriating Engel's BPS approach for purposes of analyzing the concept of disability, in that this appropriation need not be seen as having the effect of biasing or predisposing the discussion; since Engel would have been open to either a neutralist or non-neutralist account of disease, our appropriation of his approach does not beg any important questions vis-à-vis the normativist/non-normativist debate. Meantime, given this limitation, there is nothing for it but to take up the normativism/nonnormativism debate directly—which task is taken up in Chapter 4.

C. Explaining Impairment and Disability: Why the Biopsychosocial Approach is Superior to its Rivals

In sum, there are two key respects in which the biopsychosocial approach is superior to its rivals—what we might term a "macro-level" and a "micro-level" advantage, respectively. First, at the level of explanation (the "macro-level") the biopsychosocial approach captures more adequately what is "missed" by its rivals. As we saw in the previous chapter, the moral model is subject to the criticism that it potentially warrants invidious and unjustified inferences regarding the causal locus of disability; this is because it misses important non-moral causal factors, such as medical and social factors. Similarly, the medical and social models focus their attention exclusively (or primarily) on one type of factor, while missing others. The BPS approach, by contrast, points to all these factors—moral, medical, social (and, perhaps, others as well)—and holds them together in a single explanation of the disability phenomenon. For that reason, the BPS approach constitutes a more comprehensive approach, and thereby possesses greater explanatory power than its rivals.

At the "micro" level, the BPS approach makes better sense of the types of predication that are involved in attributions of 'impairment' and 'disability.' In this regard, this present work's

[26] This observation was suggested to me by H.T. Engelhardt, in personal conversation.

analysis of the concepts of impairment and disability in terms of predications of intrinsic constitutive properties versus predications of judgment proves particularly helpful. As an illustration of this, let us recall the IOM's statement (repeated at various points in different forms throughout the 1991, 1997, and 2007 IOM reports) that "...disability is not an inherent attribute of the individual but, rather, is the result of the interaction of the individual with the environment, including social norms" (1997, p. 163). Now, taken literally, this statement does not seem quite right. For the obvious question to raise is, if the interaction between the individual and her environment is a *relational* one (as the framers of the IOM models affirm), then *what exactly are the relata* of that relationship? Presumably, *something* "inherent" in the individual must form one term of the relation—if not, then what could possibly connect the "individual" to her "environment" in the first place? For that reason, it seems preferable to revise the foregoing statement along the following lines: "disability is the result of the interaction between attributes inherent in the individual and features of the environment." With this revised statement in place, we can now go on to connect it up with our broader analysis in terms of the distinction between predication of intrinsic constitutive properties and predication of judgment. Specifically, we observe that recognition of the ontological reality of *impairment* amounts to recognition of an attribute that is inherent in the individual—a constitutive property—but the further judgment of *disability* (predication of judgment) depends on various factors (social, environmental, etc.) that are external to the individual.

The foregoing observations highlight the key contribution made by the BPS approach: because the BPS approach encompasses both kinds of predication (intrinsic and extrinsic), it is thereby able to capture what the moral, medical, and social models individually miss. Thus, the BPS approach is theoretically richer and possesses greater explanatory power than its rivals, and therefore is preferable to those other approaches.

VII. CHAPTER SUMMARY/CONCLUSIONS

In this chapter we set out to accomplish two goals. First, we sought to show that the alleged conflict between the medical and social models stems from a failure to distinguish between fundamental domains of philosophical inquiry—the ontological, non-moral normative,

and moral normative domains, respectively. In setting out to accomplish this goal, we developed a negative evaluation of the contemporary literature on disability, identifying along the way two central weaknesses of that literature—namely, (1) the aforementioned assumption that the medical and social models are inherently incompatible with one another, coupled with (2) a conflation of causal explanatory accounts and social justice claims. Our discussions of these weaknesses showed that rather than being inherently incompatible with one another, the medical and social models simply address different domains of explanation, and there is thus no necessary contradiction between the two models. That having been said, our larger discussion in this work suggests that the two models, while not necessarily incompatible with one another, are nevertheless *incomplete* as stand-alone accounts. As we have argued repeatedly in this work, we need a more comprehensive account, one that incorporates the strengths of each of these models while also avoiding their respective weaknesses.

This latter point segues into the chapter's second major goal—namely, showing that a BPS approach keeps these different domains of explanation separate and distinct conceptually, but also unifies them theoretically into a coherent, comprehensive, and ultimately superior picture of disability. To that end, this chapter set out to accomplish that goal by (1) arguing for an analogy between the language of disease and illness, on the one hand, and the language of disability, on the other; (2) after developing the theoretical framework for a BPS approach, illustrating in concrete terms how a BPS approach explicitly recognizes and draws attention to the different dimensions of disability, and then unifies them into a single, integrated, coherent account; and (3) developing an explicit argument for why the BPS approach is superior, at both the "macro" and "micro" levels of explanation

At this point, we are now in a position to draw two general conclusions based on the work done in this chapter. First, there is a relevant analogy between disease and illness, on the one hand, and disability on the other—specifically, in the ways that the *language* used to speak of each is evaluative, descriptive, explanatory, and social performative, respectively. Second, given that the biopsychosocial approach explicitly recognizes and draws attention to the different dimensions of disability—specifically, the *biological, psychological,* and *social* dimensions of the

disability experience, respectively—that approach would appear to be theoretically richer than its rivals, each of which has a tendency to focus primarily, or even exclusively, on one dimension or another. Since the BPS approach helps to bring into the explanatory picture a wider range of biological, psychological, social, and other factors, the approach would appear to offer greater explanatory power than alternative approaches. On the assumption that greater explanatory power and theoretical richness counts in favor of a given type of explanation over against others,[27] this work's advocacy of a BPS approach to disability is once again vindicated.

[27] Cf. the discussion, in the Introduction to this work, of the desiderata for a "good" explanation.

Chapter 4

THE CONCEPT OF DISABILITY: ONTOLOGICAL ISSUES

I. INTRODUCTION

The central focus of Chapter 4 is an exploration of ontological issues related to the concept of disability. This includes, *inter alia,* consideration of the question whether disability is more akin to a "natural kind" or to a (merely) instrumental classification, a question which parallels the naturalism vs. non-naturalism debate in the philosophical literature addressing the nature of disease and illness. In this context, we also consider the related dispute over normativism versus non-normativism—that is, the question whether disease (and, by extension, disability) can be "read off" of the "facts of nature," so to speak, or whether identifications of states of affairs as either disease or disability are inevitably normative. (See Ch. 3 for an introductory overview of these debates.) Overall, then, the methodological approach of this chapter is to consider the naturalist/non-naturalist and normative/non-normative debates as they play out in the philosophy of medicine generally, and then to see how those discussions can be extended in the context of a comprehensive analysis of disability. Specifically, we shall consider the dialogue between Reznek (1995) and D'Amico (1995) regarding the naturalist/non-naturalist dispute, on the one hand, and the Engelhardt (1996)-Boorse (1997) dialectic regarding the normativist/non-normativist debate, on the other. Following on the heels of these exegetical sections, we develop an argument for a combined "weak naturalist/weak normativist" position as applied to disease and illness generally, and by extension to disability.

Building on and in light of the theoretical work done in Part II, the next part of the chapter—Part III—moves on to an explicit consideration of two specific ontological questions that are pertinent to a comprehensive analysis of the concept of disability. First, we consider the question whether or not there is a "species norm" with reference to (or in comparison with) which disabilities can be identified, a question raised by the naturalism/non-naturalism debate surfaced in Part II. This discussion includes consideration of two related sub-questions: (a) what is the relationship between "disability" and "normality" (or "normalcy")? and (b) is disability (merely) a

"neutral variation"?[1] Next, we consider a cluster of issues related to the question of property attribution as it pertains to disability, including whether the attribution of "disability" amounts to the attribution of an *intrinsic* or *extrinsic* property. These sections are, of course, interrelated. First we must determine whether disability is something (ontologically) real, above and beyond a merely "neutral variation." Then, we must answer the question, if disability *is* more than a mere "neutral variation," what exactly is it? That is, what are we saying of an entity when we say that "X is disabled"?

Finally, Part IV of this chapter pulls together the threads of the argument to focus our attention once again on the implications of these various theoretical investigations for our understanding of 'impairment' and 'disability' in light of the overall trajectory of this work. Here, we return to our earlier distinction between predications of intrinsic constitutive properties and predications of judgment. Part IV draws on the work done in earlier parts to draw some general conclusions regarding when attributions of 'impairment' and 'disability' involve one type of predication versus the other.

II. THEORETICAL BACKGROUND

A. Naturalism vs. Non-naturalism

There is a debate in the philosophy of medicine regarding whether or not disease is a "natural kind." Roughly speaking, a "natural kind" is a class of objects such that all members of that class share a common underlying nature—some set of properties in common in virtue of which all such objects are classed together. Simply put, the significance of natural kinds is that where a genuine "natural kind" can be identified, it becomes difficult if not impossible to claim that the kind in question is a mere "social convention," an arbitrary classification with no basis in nature (or the nature of the things themselves that constitute the class).

In the present context, the "natural kinds" debate actually encompasses *two* sub-debates: (1) is *disease* a natural kind?, and (2) are *diseases* natural kinds? That is, even if there is no underlying nature common to all disease as such, might individual diseases (or, perhaps, classes

[1] In Chapter 5, we will consider a related argument, the "form of culture" argument, according to which disability is (merely) a form of culture just like any other.

of diseases) share a common underlying nature such that they are appropriately termed "natural kinds"?

The natural kinds debate has played out in numerous venues, including the pages of *The Journal of Medicine and Philosophy,* where Lawrie Reznek and Robert D'Amico debated the issue in a set of articles that appeared in 1995. Our discussion of this issue will track the Reznek-D'Amico debate, with a view toward highlighting those aspects of the debate that are particularly relevant to our broader consideration of the nature of disability.

According to Lawrie Reznek, disease is not a natural kind term.[2] In response, Robert D'Amico argues against Reznek in defense of an understanding of disease in terms of natural kinds. We begin with an explication of D'Amico's argument against Reznek.

In an article entitled "Is Disease a Natural Kind?" Robert D'Amico (1995) argues, *pace* Lawrie Reznek, that, indeed, disease *is* a natural kind. D'Amico proceeds by taking up, in turn, each of Reznek's two major arguments against a naturalistic understanding of disease, seeking to show why those arguments fail. D'Amico notes that Reznek's overall approach revolves around two arguments, a "stronger" and "weaker" one; he then contends that Reznek's "stronger" argument—an "a priori, conceptual argument"—in fact depends upon his "weaker" argument, one which rests on empirical rather than conceptual grounds. Along the way, D'Amico challenges Reznek's account of natural kind terms, suggesting that other accounts are available, and seeks to counter Reznek's claim that an affirmation of a naturalistic account of disease would effectively preclude the existence of classificatory conventions in medicine.

D'Amico begins by clarifying the question at hand and its significance for the broader issue of understanding the nature of disease. In brief, the question comes down to one of whether or not there is a natural "fact of the matter" on the basis of which disease classifications are made: "Are classifications of disease conventions of labeling or the result of discovering some fact of the matter in nature?" (D'Amico, 1995, pp. 551-552). If one answers by affirming the second half of the disjunct—that is, that disease classifications result from a discovery of "some

[2] This represents a negative answer to the first question listed above. Reznek limits his discussion exclusively to this first question; see Reznek (1995, pp. 572-573) for his rationale for this approach.

fact of the matter in nature"—then we are forced to accept the conclusion that *earlier* classifications that have now been rejected as false (e.g., the classification of "drapetomania"[3] as a disease) were either (a) the result of "past failures in research (perhaps due to bias or prejudice)" or else (b) "as yet unresolved questions." In either case, it is plausible on such an understanding to assume that further research will shed light on the *real* nature of the condition in question. By contrast, on a strictly non-naturalistic understanding, no amount of further (empirical) research could clarify such questions; rather, the matter can be settled only by way of conventional agreement—which agreement, though it may engender controversy, cannot be resolved through further research alone (D'Amico, 1995, pp. 551-552).

In short, D'Amico wishes to defend a naturalistic account which sees disease as a legitimate object of scientific inquiry. As D'Amico puts it, "naturalists are committed to the term 'disease' being a natural kind term.... If disease names a natural kind then all diseases share the same underlying nature, which is the object of scientific inquiry" (D'Amico, 1995, p. 552).[4]

Central to D'Amico's argument is his contention that there are other accounts of natural kinds available to the naturalist than the account utilized by Reznek. In this regard, D'Amico identifies three distinct accounts of natural kinds: (1) "empirical generalization-governed," (2) "law-governed," and (3) "custom-governed" natural kinds, respectively. The first of these traces its philosophical roots to John Stuart Mill, and relies upon a non-essentialist approach according to which membership in a natural kind is determined not by the possession of a set of "necessary and sufficient conditions," i.e., a precise set of properties shared by *all* members of that class, but rather by the possession of "an adequate number of these properties," which possession is "sufficient for falling within the extension of the [natural kind] term" (D'Amico, 1995, p. 554).[5]

---

[3] In his "Report on the Diseases and Physical Peculiarities of the Negro Race." nineteenth-century physician Samuel Cartwright (1851/1981) discusses, among other conditions thought to be endemic to the "Negro race," the "disease" of "drapetomania, or the disease causing slaves to run away" (p. 318). Similarly, masturbation was once thought to be a disease—or, more precisely, a cause of disease (see Engelhardt, 1981).

[4] This is, in effect, an affirmative answer to both of the questions—(1) is *disease* a natural kind?, and (2) are *diseases* natural kinds?—encompassed by the natural kinds debate.

[5] This approach, D'Amico explains, is "similar to recent ideas about 'property clusters' or 'criterial attribute theories,'" according to which "it is partly a conceptual matter as to what properties belong to the 'cluster'" (D'Amico, 1995, p. 554).

A brief discussion of a distinction between two different types of concepts—specifically, "essential" versus "cluster" concepts—may be particularly helpful here. A concept can be defined by reference to essential properties or characteristics that never change and that serve as criteria, all of which must be met, for a concept to apply. This would be an *essential concept.* Thus, for Aristotelian metaphysics, the concept of man is an essential concept and is defined as "rational animality." (Aristotelian essential concepts are formed by adding a specific difference, in this case 'rational,' to a genus, such as 'animal.') To predicate truly "human" of an entity in a proposition, 'S is P' (where 'P' = human), then the essential property or criterion, "rational animality," must be found in the entity referred to by 'S.'

By contrast, a *cluster concept* is not analyzed in terms of essential properties or criteria, all of which must be found in the referent of 'S' in an 'S is P' proposition. Arguably, the highly contested concept of "human dignity" may be an example of a cluster concept. On various accounts of human dignity, the concept encompasses a range of features, including (but not necessarily limited to) such things as "respect," "power," "enlightenment," "well-being," "health," "skill," "affection," and "rectitude" (see Shestak, 1998). Predication of "dignity" in one context might appeal to respect and power, but in another context to health and skill. From the perspective of cluster concepts, both predications would be true, an impossibility from the perspective of essential concepts. One way to read Wittgenstein on "family resemblance" is that family-resemblance concepts are cluster rather than essential concepts.

Practically speaking, cluster concepts have considerable political advantage: they allow people of diverse views and commitments to agree on things without having to have an essential, i.e., precisely the same, account of the concepts being used. Appeal to cluster concepts plays a major role in international declarations and statements. For example, UNESCO's Universal Declaration on Bioethics and Human Rights (http://portal.unesco.org/en/ev.php URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) appeals to dignity in just this way. In doing so, it is part of an intellectual tradition that reaches back to the 1947 UN Declaration on Human Rights. The goal is to get agreement, albeit at an abstract level, and then put the declaration into practice. As the declaration is applied, the cluster concept comes to bear in different ways and more fully over time. The political process, in a sense, "wills" the truth of the concept's application. There is a considerable debt to classical American pragmatism in this approach. The recent "Convention on the Rights of Persons with Disabilities" represents well this sort of approach—while discussing at length the "rights" of persons with disabilities, the document never explicitly defines disability as such. This was a deliberate omission, as the drafters of the document were divided regarding how to characterize disability conceptually. (The text of the Convention and an overview of the process whereby it was developed is available at the United Nations Enable website: http://www.un.org/disabilities/).

The import of this notion is that we might be able to see discussions of "disability" as involving the use of something like Wittgensteinian "family resemblances" or "cluster concepts"—that is, concepts that pick out different properties from among a "cluster" of properties, depending on what is considered relevant to different purposes. Another way of putting this point is to say that different parties to the disputes over disability may in fact be operating with disparate *conceptualizations* of the disability concept. Thus, when different individuals speak of "disability," they may be referring to the same generalized *concept* (a "cluster" of properties), yet employing different *conceptions* (i.e., picking out different elements of the "cluster"), given their differing purposes and/or agendas.

Depending on the purposes or agendas in view, one might, for example, have a professional clinical, public policy, or medical pension concept of disability, each of which have some elements in common but none of which have all elements in common—hence, the designation as a "cluster concept." A variety of properties might be seen as being a part of the "cluster"—e.g., "departures from normal function," "major functional deficit," being an "undesirable condition," and perhaps others as well—some of which would be appealed to in certain contexts, while others are appealed to in other contexts.

Cashing out "disability" in terms of "cluster concepts" may, in turn, have rich explanatory power in accounting for the previously-identified confusions in the extant literature on disability. So, for example, what appears to be the use of a "medical model" of disability may in fact be

The second understanding of natural kind terms—which, D'Amico says, is the one upon which Reznek relies exclusively—is an "essentialist" approach similar to that advanced by the likes of Putnam (1975) and Saul Kripke (1980). "In this tradition," according to D'Amico, "the notion of a kind refers to the lawlike relations that hold for the essential or microphysical structure of things" (D'Amico, 1995, pp. 554-555). Key to this understanding of natural kinds is a distinction between the surface features of a class of things—what Putnam calls a "stereotype"—and the underlying microphysical structure shared by that class of objects. It is this "underlying structure" that defines a natural kind. Thus,

> a "realist taxonomy" (to use Reznek's phrase) of things in the world will tend to sort out particulars into groupings that diverge from the macro-level similarities available to sense perception and captured by the usual descriptions of the kind invented for social and cultural purposes. This picture holds that the extension of the term for a kind is fixed by the underlying structure, studied by science, independently of how the kind is described in what Putnam calls its "stereotype" (D'Amico, 1995, pp. 554-555).

According to D'Amico's reconstruction of Reznek's argument, "[i]t is this effort at a very clear dividing line, unlike the vagueness in Mill's account, that Reznek exploits in his argument that disease is a domain admitting only of stereotypes" (D'Amico, 1995, pp. 554-555)—that is, that

---

simply the employment of a "cluster concept" that picks out "medical" features of a disability concept, for purposes of generating a treatment plan in a clinical context. Alternatively, when broader public policies are in view, advocates may be appealing to a different part of the "cluster" to advance what appears to be a "social model" of disability. The basic idea, then, would be that different models pick out different kinds of explanatory features—that is, the medical model picks out medical-scientific causal factors; the social model picks out non-moral normative features (e.g., aesthetic values regarding form and function); and the moral model picks out moral normative features (e.g. moral causes of or responsibility for disability)—as they are considered relevant to different explanatory contexts and purposes. It may be that both sides to the "medical versus social model" dispute would acknowledge and recognize features of disability picked out by the opposing side—yet, given their respective agendas, they are emphasizing certain elements of the "cluster" over against others. In this way, then, the appearance of irreducible conflict between advocates of the medical and social models may turn out to be somewhat illusory.

For more on concepts generally, and "cluster concepts" in particular, see Boer (1974), Cooper (1972), Margolis & Laurence (2006), and Parsons (1973); for a technical discussion of the cogency (or lack thereof) of the "concept-conception" distinction, see Higginbotham (1998), Macià (1998), Jacob (1998), and Ezcurdia (1998).

I am grateful to Laurence B. McCullough for alerting me to the potential relevance of the essential concept/cluster concept distinction, and for providing me with some of the language used in this note.

diseases are grouped together solely on the basis of similarities in their surface features, and not on the basis of any underlying shared nature (because, according to Reznek, there *is* no such common underlying nature in the first place).

Finally, a third approach to understanding natural kinds represents a sort of middle road between the other two—namely, understanding natural kinds as "custom-governed." On this account, which D'Amico attributes to Peter French (1983), "objects are classified both with regard to facts of the matter in nature and yet also by decisions about the classification which reflect our social usage and practice rather than the natural world" (D'Amico, 1995, p. 555). In this way, "[c]ustom-governed kinds stand as a third option between objective facts determined by the world and conventions determined only by argument and choice" (D'Amico, 1995, p. 555).

Turning now to a detailed analysis of and response to Reznek's understanding of diseases as "law-governed kinds," D'Amico first notes Reznek's observation that if there *were* "a set of underlying properties shared by all conditions called diseases"—that is, "a single underlying process or structure underlying the diversity of symptoms and etiologies"—then we should reasonably expect there to be "a fact of the matter distinguishing diseases from other biological functions" (D'Amico, 1995, p. 556). Reznek thinks that there is *not* such a "fact of the matter," whereas D'Amico thinks there *is* such a thing. In support of this contention, D'Amico cites two factors which, he says, "reinforce the picture that diseases are natural kinds" (D'Amico, 1995, p. 556).

The first factor that D'Amico appeals to is what Putnam termed a "linguistic division of labor," according to which "experts" override lay opinion regarding the definition and extension of natural kind terms. More precisely, the idea here is that "knowledge of the nature of a kind is specialized and technical" (D'Amico, 1995, p. 556). Thus,

> the stereotype for identifying kinds is a rough guide often designed for practical situations and keyed to those properties readily observable. But the identification of kinds by their stereotypes is always "trumped" by an expert who determines whether the particular thing in question falls into the extension of the kind (D'Amico, 1995, p. 556).

On D'Amico's view, the fact that such an "expertise" has developed in the field of medicine gives us good reason to think that diseases are natural kind terms.[6]

A second factor to which D'Amico appeals is the history of medicine itself. As D'Amico observes, numerous historical instances can be adduced of "disease" classifications that were later revised after further research revealed a different underlying nature than originally supposed.[7] These historical examples, D'Amico says, "strongly support the notion that the identification of a disease is not a purely conventional decision, whereas such a reform of usage would be pointless for other than reasons of convenience or practicality" (D'Amico, 1995, pp. 556-557). Throughout the history of medicine, disease classifications have not typically proceeded

> from mere convenience or arbitrary choice, but from a first reliance on descriptive accounts worked out prior to some access to the underlying causal processes of these conditions. Once the underlying nature is discovered, ideally a specific virus or bacteria, the previous descriptive account is either reformed or adjusted to the now discovered underlying disease process (D'Amico, 1995, pp. 556-557).[8]

So what, then, *is* this common "underlying nature" on the basis of which various conditions are classed as "disease"? D'Amico considers candidates that have frequently been

---

[6] As D'Amico puts the point, "...the emergence of a medical expertise for the identification of these conditions lends support to the naturalistic account" (D'Amico, 1995, p. 556). Of course, one might wonder in this context, suppose it turned out to be the case that the "experts" were (merely) experts at *conventional classification*? If this were so, then the "emergence of a medical expertise" would seem to show only that certain individuals were invested with authority to define classifications—not that there *are* natural kinds as such!

[7] As illustrations of this claim, D'Amico points to (1) the (initially) mistaken grouping of diseases together based on observable features (e.g., syphilis and gonorrhea); (2) symptoms mistakenly identified with disease (e.g., "fevers"); (3) cases in which no effective treatment for a condition was available until the identification of the relevant disease entity responsible for that condition (e.g., tuberculosis); and (4) the fact that, over time, various conditions have either been added to or removed from the list of diseases on the basis of further (empirical) research regarding the underlying natures of the respective conditions (e.g., "hysterical paralysis" was removed from the list, whereas epilepsy was added).

[8] This latter point regarding the typical historical *process* by which disease classifications have been made—that is, moving *from* initial descriptive observations *to* an account of "underlying causal processes"—helps to strengthen D'Amico's case here. Otherwise, it is difficult to see how the mere inclusion or exclusion of items in the disease category supports *any* conclusion, one way or the other, regarding the question of diseases as natural kinds. For without this "discovery" of an underlying "causal process" that *is in fact (ontologically) there,* it would seem to be open to the conventionalist to claim that the seemingly arbitrary addition to and removal of various items from the list of "diseases" simply shows the conventionalist account to be correct after all.

offered, but which must inevitably be found wanting. First, some have suggested "statistical abnormality" as the underlying nature that constitutes the class of diseases. But this is problematic because this would render such statistically abnormal conditions as having type-O blood a disease—clearly a false classification. Second, the "disease" category cannot be defined by "pain and suffering," for this would identify as diseases states or conditions that are "normal biological processes" (e.g., childbirth or teething). Finally, it cannot be the state of "being undesirable" that unifies the disease class, for then "that would mean shortsightedness, need for sleep, or simply being overweight would have to fall within the extension of disease"—again, results that are clearly counterintuitive, to say the least.[9] Reznek, of course, takes the failure of these "traditional attempts at stating what is the common explanatory nature of disease" to mean that there *is,* in fact, no such "common explanatory nature" in the first place.

At this point D'Amico turns to a direct consideration of Reznek's two main positive arguments in support of this claim. The first argument runs along the following lines. For various reasons it is impossible to distinguish (in terms of a common underlying nature) "diseases" from "injuries," "accidents," and "disabilities" (D'Amico, 1995, p. 557). Instead, all such conditions fall under the heading of "harmful conditions"—to the extent that they can be distinguished at all, it is only on the basis of our judgments regarding their relative degrees of "harmfulness" rather than any putative differences in their underlying nature. Our systems of classification, then, reflect "an agreement about what conditions are harmful or undesirable to humans and that judgment will rest on our culture's values and preferences" (D'Amico, 1995, p. 558).[10]

There are, D'Amico counters, several weaknesses in Reznek's argument here. First, it is possible that our present classification systems are "faulty." Why should we assume that our "theoretical account of disease" must "capture or match" either the "current classifications of the medical community" or of "common sense"? Instead, D'Amico says, the history of medicine that

---

[9] With respect to "being undesirable," we might say something similar regarding disability—namely, that the mere state of "being undesirable" is not sufficient to render that condition a "disability." The further question, whether "being undesirable" is a *necessary* condition for either disease or disability is a separate question.

[10] But of course, gunshot wounds, accident traumas, and diseases—the examples to which Reznek appeals in support of this claim—are all "harmful." So, the question then becomes, what distinguishes *them* from one another?

he has previously rehearsed gives us reason to suspect that present classifications may be faulty, just as certain past classifications have been as well.

Second, the fact that we cannot discern a "common explanatory nature" in the "surface diversity" of the set of conditions currently classified as disease, and the fact that we may not currently know what that "common explanatory nature" is, does not mean that an underlying common explanatory nature will not *eventually* be discovered. It would only mean this if one presupposed, from the outset, that such an underlying common explanatory nature could not possibly exist. That is,

> to say that the various diseases we have currently labeled as such are too diverse and heterogeneous is to reach that judgment on the basis of the observable features of the condition that serve common understanding and unaided perceptual diagnosis of diseases. The apparent diversity at the level of these stereotypes of the kind in question does not alone establish that there will not be a common underlying explanatory nature, without simply assuming that the account of natural kinds is wrong in this case (D'Amico, 1995, p. 559).

Indeed, D'Amico observes, "[s]uch surface diversity is characteristic of many scientific disciplines" (D'Amico, 1995, p. 559).

A third and final problem to which D'Amico draws attention is that there are specific disease entities such that various instances of the disease exhibit a variety of surface manifestations (e.g., in symptoms), but which are nonetheless best accounted for in terms of natural kinds. For example, patients with multiple sclerosis (MS) typically exhibit markedly different symptoms and other empirically observable signs—yet, just as clearly, MS itself has a common underlying explanatory nature, even if we do not yet know (precisely) what it is. As D'Amico puts it,

> all patients with multiple sclerosis (MS) have the same underlying explanatory nature, even given the diversity of symptoms and empirical manifestations, and thus MS forms a natural kind, though it remains unknown as to what the underlying condition is. Whatever

> it turns out to be, upon the result of such research, it will be what we were referring to when we said a patient has MS (D'Amico, 1995, pp. 559-560).

Thus, D'Amico concludes, "the disease entity is a natural kind, if anything is a natural kind" (D'Amico, 1995, pp. 559-560).

As D'Amico sees it, Reznek has failed to undermine the naturalistic understanding of disease on the basis of "doubts about existing classifications or the fact that a common underlying structure has yet to be discovered" (D'Amico, 1995, p. 560). The former worry—i.e., entities have over time been added to and removed from the list of "diseases," thus casting doubt on our confidence that our current classifications have somehow captured an "underlying explanatory nature" accurately—can just as easily be used to support a naturalistic account: previous classifications were revised as further research discovered the underlying nature of things. The latter worry—that "a common underlying structure has yet to be discovered"—does nothing to show that such a structure will not (someday) be discovered. So, D'Amico concludes, these sorts of empirical arguments will not do the trick for Reznek. Instead, what Reznek needs is a "conceptual" argument,

> some conceptual argument showing that disease classification is just like the classification of things as furniture, showing why these concepts do not admit of kinds, and making this case independently of doubts about existing classifications or the fact that a common underlying structure has yet to be discovered (D'Amico, 1995, p. 560).

As it happens, Reznek does advance an "a priori, conceptual" argument along these lines, and it is to that argument that D'Amico now turns his attention. In a nutshell, Reznek's argument—as reconstructed here by D'Amico—is that (1) "[i]f we know something is a disease *prior* to any empirical discovery about its nature, then disease is not a natural kind," (2) we *can* in fact know that something is a disease prior to such empirical discovery, and therefore, (3) disease is not a natural kind (D'Amico, 1995, pp. 560-561). In support of this conclusion, Reznek develops a thought experiment similar in form to Putnam's "Twin Earth" thought experiment in which what is called "H_20" on earth has the same macro-features, or "stereotypes," as what is called "XYZ" on "Twin Earth," but the two substances have different microstructures. Putnam concludes that "H_20"

and "XYZ" are, in fact, *not* identical substances even though they are called "water," have the same surface features (clear, liquid, etc.), and fulfill the same functional roles (quenching thirst, etc.) on both planets. On Putnam's view, "water is a natural kind precisely because what fixes the extension of the kind is the microstructure and not the stereotype" (D'Amico, 1995, p. 561).

In his own thought experiment, Reznek changes the details slightly to reflect a medical context. Here, the contrast is between conditions caused by fungal infections and those caused by bacterial infections:

> Suppose we discovered that all diseases were due to fungal infections, and that other pathological conditions were due to bacterial infections. We know *a priori* that if we came across a condition that was due to a bacterial infection, but which consisted in our developing green spots, fever, malaise, and the complete failure of our blood to clot, it would be a disease. Because we know that it would be a disease *prior* to the discovery of its nature, being a disease cannot consist in membership to some higher-order natural kind – that is, it cannot consist in the possession of a special sort of nature. And hence diseases do not constitute a natural kind (Reznek, 1987, p. 70, quoted in D'Amico, 1997, p. 561).[11]

Reznek's appropriation of Putnam's thought experiment is clearly intended to show that diseases are *not* in fact natural kinds. On Reznek's view, the thought experiment illuminates the fact that we pick out conditions as "diseases" *solely* on the basis of their "observable features" and "the judgment that the condition is harmful" (D'Amico, 1995, p. 562), not by reference to their microphysical structures. Hence, Reznek concludes, our conceptual practices themselves undermine the naturalistic account of disease. The problem with this line of reasoning, according

---

[11] In his (1997), Reznek provides a shortened version of this thought experiment:
> Suppose we (contra fact) found that all diseases shared a common nature distinct from other pathological conditions. This would not show that disease was a natural kind. Suppose we found they were all fungal infections, and then happened upon a condition characterized by fever, green spots and death from coagulation failure that was due to a different nature (say a bacterial infection). I argued that we know *prior* to the discovery of this nature that it is a disease simply because this is how our concept is used (Reznek, 1997, p. 580).

Of course, Reznek's thought experiment raises the further question of what it is that places a particular condition in the class of conditions that *cause* these undesirable effects—arguably, its *underlying nature*.

to D'Amico, is that "[t]he observable features of the condition and the judgment that the condition is harmful would pick out many conditions that are not diseases, such as car accidents and being overweight" (D'Amico, 1995, p. 562). Moreover, D'Amico says, Reznek's argument at this point is essentially question-begging, for in order for Reznek's argument to go through, he must presuppose that the term 'disease' is being used "nominalistically"—that is, as a (mere) functional descriptor, such that "'we know it would be a disease *prior* to the discovery of its nature'" (D'Amico, 1995, p. 562, quoting Reznek, 1995, p. 580)—rather than realistically, which, of course, is precisely the question in dispute.

On D'Amico's view, then, Reznek's a priori, conceptual argument fails, leaving him only with his weaker, empirical argument appealing to "macro-level diversity" (D'Amico, 1995, p. 564). But this empirical argument, D'Amico says, succeeds only in establishing that, "as yet, disease classifications are not guided by a single theoretical notion, not that there cannot be such a notion" (D'Amico, 1995, p. 564). Thus, D'Amico concludes, Reznek has not met the burden of proof needed to show the naturalist position to be false. As D'Amico puts it, "all the naturalist argument requires is that whatever theoretical approach prevails, and whatever human interests play a role in such inquiry, that a thing's underlying nature, if there is one, is neither invented nor imposed" (D'Amico, 1995, p. 565). This still leaves open the possibility that, as Reznek argues, certain "evaluative concepts" necessarily play a role in medicine,[12] as well as that certain "aspects of medical classifications are interest-relative and thus, in some sense, conventional" (D'Amico, 1995, p. 566). Instead, D'Amico goes on to say,

> I think a more flexible philosophical account of natural kinds, as found in Mill for example, could have accommodated Reznek's concerns without abandoning a concept of disease which properly separates what is a matter of how the world is from what humans value and then variously choose to prefer (D'Amico, 1995, p. 566).

***

Having laid out the contours of the "naturalism/non-naturalism" debate in the philosophy of medicine, we can now move on to consider the related "normativism/non-normativism" debate.

---

[12] As we will see in chapter 5, this will prove to be a significant point.

Before proceeding further, however, it bears emphasizing that our aim here is not to settle definitively either of these two disputes. For present purposes, it will suffice simply to observe that D'Amico's counterarguments to Reznek's thesis would appear to give us plausible reasons for thinking that disease classifications are not *mere,* or *solely,* instrumental classifications, while nevertheless allowing that instrumental concerns do enter into such classifications to some extent. The relevance of this for our larger project will become clearer as the chapter progresses.

B. Normativism vs. Non-normativism: The Engelhardt-Boorse Dialectic

We turn our attention now to another key theoretical dispute—namely, the normativism versus non-normativism debate. The debate over normativism versus non-normativism (or neutralism) can be summarized along the following lines. Christopher Boorse is a prominent representative of the "naturalist" position vis-à-vis determinations of disease and illness. A self-styled "unrepentant naturalist," he can also be characterized as a "neutralist": on his "Biostatistical Theory" (BST), "the classification of human states as healthy or diseased is an objective matter, to be read off the biological facts of nature without need of value judgments" (Boorse, 1997, p. 4). For Boorse, "[t]heoretical health... is the absence of disease; disease is only statistically species-subnormal biological part-function...." (Boorse, 1997, p. 4). This definition flows out of Boorse's reliance upon what he terms the "normal-pathological" distinction, which is specified as follows:

1. The *reference class* is a natural class of organisms of uniform functional design; specifically, an age group of a sex of a species.
2. A *normal function* of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction.
3. A *disease* is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency [a "species-atypical level of a species-typical function"], or a limitation on functional ability caused by environmental agents.
4. *Health* is the absence of disease (Boorse, 1997, p. 8).

On Boorse's earlier view, "illness" was a value-laden subset of the "disease" category. The basic idea was that we can distinguish between "theoretical" concepts of health, on the one

hand, and "practical" concepts of health, on the other; the former, Boorse believed, was primarily the province of the pathologist, whereas the clinician was more interested in the latter. The thought, then, was to distinguish "value-free theoretical health from a value-laden practical counterpart, freedom from illness" (Boorse, 1997, p. 11). On such an understanding, "illness" was "a subclass of disease, including diseases serious enough to have certain normative features." Those normative features were three-fold:

> A disease is an illness only if it is serious enough to be incapacitating, and therefore is
>
> a. undesirable for its bearer;
> b. a title to special treatment; and
> c. a valid excuse for normally criticizable behavior (Boorse, 1975, p. 61, quoted in Boorse, 1997, p. 11).

Boorse eventually changed his view on the value-ladenness of "illness." Although he still believes in the soundness of the distinction between "value-free theoretical" and "value-laden practical" concepts of health, he now believes that both "disease" and "illness" are equally value-free and *theoretical* concepts—that is, that they both fall under the domain of the first disjunct of the value-free vs. value-laden distinction. Boorse's reasons for this change of view are two-fold. First, one of the reasons he had initially embraced a value-laden notion of "illness" was that the term does not seem to be applicable to plants or animals; instead, it seemed to be applicable only to humans. By contrast, we *do* frequently refer to both plants and animals as "sick." And we do this despite the fact that, as Boorse puts it, "there seems to be no semantic difference between 'ill' and 'sick'" (Boorse, 1997, p. 11). Indeed, Boorse says, "[t]he two terms seem to differ only in that 'ill' is more elevated in tone, possibly because it is more common in England, where things have greater dignity" (Boorse, 1997, p. 11). But if that is the case, then "the reason we do not call sick animals 'ill' is the same reason we don't call dead animals 'deceased' (Boorse, 1997, p. 11). And if *that* is the case, then there really is no semantic difference between the two terms, from which it follows that if one is value-neutral, the other must be as well.

This leads Boorse to his second reason for changing his views regarding the value-ladenness of 'illness'—which reason he takes to settle decisively the question of the value-neutrality of 'illness' as well as 'disease.' As Boorse explains it,

> [t]he difference between disease and illness does not, in fact, seem to be a difference of severity. Usually when I am sick, I am less disabled from my normal activities than I would be if blind or paraplegic. Yet blindness and paraplegia are not illnesses, while a mild case of flu is. Why? Not because illness must be a process, since the same point could be made with severe progressive blindness. Rather, it is because "sick" (or "ill") refers to systemic rather than local disease, to disease which in some sense incapacitates by permeating the whole organism, as do infectious diseases via blood-borne substances and disruption of central homeostasis. But this term "systemic," though vague, is a physiological or pathological term, not an evaluative one. Consequently, I now consider "disease" and "illness" equally value-free (Boorse, 1997, p. 12).[13]

Beyond this point the specific details of Boorse's theory are not important for present purposes; what is relevant is to highlight the fact that, on Boorse's account, 'disease' is a natural kind: diseases are "out there" in nature, not mere instrumental classifications.[14] Moreover, determinations of health and disease are made with reference to "normal functional ability," which in turn is referenced to "statistically typical contribution" to "individual survival and reproduction"—what Boorse labels the "physiologist's goals." In short, for Boorse a disease is any statistically-significant deviation from "normal functioning" that impairs the individual survival and/or reproduction of a member of a given species. That is to say, Boorse is convinced that one can discern in the products of evolution a "species design," understood in terms of the promotion of individual survival and reproduction;[15] 'disease,' then, is a statistically-significant deviation from

---

[13] See Boorse (1997, pp. 6-16) for Boorse's summary of his BST, including an explanation of his change in views regarding "illness."

[14] Cf. the discussion of the Reznek-D'Amico debate regarding disease as a "natural kind," earlier in this chapter.

[15] Boorse provides the following definition of 'species-design':

> In modern terms, species design is the internal functional organization typical of species members, which (as regards somatic medicine) forms the subject matter of physiology: the interlocking hierarchy of functional processes, at every level from organelle to cell to

that species design. In this way, Boorse believes, his theory of disease is value-neutral. And it is here that the battle is joined with his critics.

For Boorse's critics, the most obvious point of attack is to raise doubts as to the alleged "value-neutrality" of the BST. Scott DeVito (2005), for example, argues that the BST is value-laden on at least two levels. First, the BST is value-laden at the "choice level"—namely, the choice of the "physiologist's goals." For one thing, DeVito notes, physiologists themselves choose to direct their attention to "individual survival" (or "life") and "reproduction" as a function of their own instrumental interests (presumably, they might choose to focus their attention elsewhere were they to have different interests). Second, the choice of the physiologists' goals is *itself* a normative choice: why appeal to the "goals" of *physiologists* as opposed to biologists, or physicists, or chemists, or whatever? DeVito further argues that the BST is value-laden at the level of the choice of "criteria"—that is to say, in the emphasis on *life* and *reproduction* as criteria with reference to which "normal function" is to be determined. The problem here is that this assumes that life and reproduction are *goods* to be valued: but this is, of course, a normative judgment, and hence the BST is evaluative at this level as well.

Aside from questioning the value-neutrality of BST, many critics have also questioned the *adequacy* of BST as an account of disease. DeVito, for example, notes that by focusing its attention on individual survival and reproduction, the BST ignores other relevant concerns that people often have when it comes to determining whether a condition is to be counted as a "disease"—for example, quality-of-life considerations. In a nutshell, people are concerned about things other than survival and reproduction, and the BST does not seem able to accommodate this fact.

A plethora of other criticisms have been lodged against the BST, including a raft of counterexamples aimed at showing the BST to be too narrow (e.g., it would not count conditions such as hypertension, benign prostatic hyperplasia [BPH], or arteriosclerosis as diseases, because such conditions are statistically "typical"), and that it fails to account for the actual practice of medicine: there are, for example, many conditions for which people seek treatment

---

tissue to organ to gross behavior, by which organisms of a given species maintain and renew their life (Boorse, 1997, p. 7).

that would not be considered "diseases" according to the BST.[16] Engelhardt, in fact, has gone so far as to claim that Boorse has succeeded merely in reconstructing (i.e., offering a rational account of) *biology* rather than *medicine* (Engelhardt, 1996, p. 203).

In light of these sorts of concerns, many philosophers of medicine have felt compelled to embrace some form of normativism vis-à-vis disease concepts. Engelhardt (1996, Ch. 5., pp. 189-238), for example, characterizes "disease" as a conceptual apparatus that enables one, among other things, to create a treatment warrant: medicine is, on Engelhardt's view, fundamentally concerned with *treatment* of "clinical problems," or conditions that are considered to be undesirable for one reason or another. Such treatment warrants are devised against the backdrop of ideals of form and function, freedom from pain, and desired life span. Medical language—encompassing concepts of disease, illness, disability, and so forth—has four distinct but interrelated functions (see Engelhardt, 1996, ch. 5). First, medical language is evaluative: terming a condition a "disease" is to render a negative judgment. Second, medical language is descriptive: seeing is always "seeing as," and we thus "see" diseases within a framework of descriptive expectations. Similarly, disease language is explanatory, serving to place a disease within a web of causal explanations which allow for further explanations, treatments, and prognoses. Finally, disease language is social performative: to pronounce someone "diseased" or "ill" is to place that person within a matrix of social expectations and, potentially, to burden that individual as well (e.g., with stigmatization). The upshot: determinations of health and disease have a wide array of evaluative components.[17]

---

[16] In response to this point, Boorse might simply acknowledge that people do seek "treatment" for conditions that are not, in fact, *diseases*—but then insist that this does nothing to show disease *itself* to be an evaluative notion (see Boorse, 1997, pp. 23-28 for an argument along these lines). Of course, the rejoinder to Boorse would be that this just gives us all the more reason to think that medicine is interested in calling states of affairs "diseases" precisely *because* they are (or create) useful treatment warrants.

[17] To be sure, problems can be raised for normativist accounts as well. To cite just one fairly straightforward example: Clouser, Culver, and Gert (1997) have developed what they term a concept of "malady," which they intend as an alternative genus term to the concept of disease. CGC define "malady" as follows: "Individuals have a malady if and only if they have a condition, other than their rational beliefs and desires, such that they are incurring, or are at significantly increased risk of incurring, a harm or evil (death, disability, pain, loss of freedom, loss of pleasure) in the absence of a distinct sustaining cause." Upon reflection, an immediate counterexample springs to mind—namely, infertility resulting from a husband's low sperm count. By most people's lights, such infertility *would* be considered a "disease"—indeed, people routinely

***

As with the previous section, we pause momentarily to reiterate the fact that we are not attempting here to settle in any *decisive* way the normativism/non-normativism debate in the philosophy of medicine—such a project would go well beyond the scope of this present work. Instead, the most salient point to be gleaned from the foregoing material is that we have good reason to think that, at the end of the day, identifications of states of affairs as disease are inevitably (at least partially) normative. This claim, as we will see in the following section, when combined with the insights of the previous section, figure into an argument for the adoption of a "weak naturalist/weak normativist" position regarding disease and illness—which, for purposes of this work, will in turn serve as the grounds for extending that position to the notion of disability as well. In developing this argument, the next section demonstrates the relevance of the theoretical background discussed at length in these first two sections.

C. An Argument for "Weak Naturalism" and "Weak Normativism" vis-à-vis Disease, Illness, and Disability

In light of the Reznek/D'Amico and Engelhardt/Boorse debates, we can draw several conclusions. On the one hand, our identification of states of affairs as disease, illness, and disability are, in some ways and to some extent, constrained by nature—we cannot call just *anything* a disease, illness, or disability. For example, we would not refer to human beings' lack of ability to fly (without mechanical assistance, such as that provided by airplanes) as a *disability*—since *no* human beings are able to fly (because *no* human beings have feathered wings), it seems reasonable to conclude that the "species design" for human beings simply does not include "being able to fly" among its specifications.[18] Hence, although we can literally utter the

---

seek medical treatment for this sort of condition—yet, on CGC's account of 'malady,' such infertility would *not* count as a disease (because it does not cause pain, death, etc.). The relevant conclusion to draw here, however, is not that normativism as such is flawed. Rather, we should conclude that not all forms of normativism will succeed, and thus one should take care in how one constructs one's normative theory. The development of a *complete*, full-fledged normativist theory—either of disease or disability—is, of course, beyond the scope of this present work.

[18] As Shakespeare puts it, in the context of his critique of the social model's vision of a "barrier-free utopia,"

> [t]hose who adopt the social model are relativist, in that they claim that having an impairment is a different but equal form of embodiment to not having an impairment. From a social model perspective, it is not the form of embodiment which is the problem,

words, it would make no sense to say that not being able to fly counts as a "disability." So "species-typicality," in this sense, sets a certain threshold for what will count as "disease," "illness," and "disability"; hence, we must reject a *strictly* non-naturalistic account of these terms.

On the other hand, when it comes to determinations of disease, illness, and disability, not *everything* is found "in nature." That is, we do indeed bring values (social, moral, aesthetic, epistemic, and so forth) to the equation. There is, in other words, always a values overlay involved in determinations of states of affairs as disease, illness, and disability. Thus, not being able to stand or walk without mechanical assistance typically *does* count as a disability, in part because of the social value we place on such activities, especially in certain contexts. For example, in the context of work,[19] being able to stand or walk without mechanical assistance may be vital for certain forms of employment, but not for others. Hence, in some instances, an individual may be considered "disabled," but not in others. These sorts of issues have arisen in the context of legal action related to the Americans with Disabilities Act (Waterstone, Siegal, Hill, & Blanck, 2006). A person may be considered "totally disabled" if she is, by virtue of accident or illness, unable to perform *any* job in the field for which she has been trained, even though she *could* perform a job in some other field. These sorts of determinations of "disabled" or "not disabled" clearly reflect the ingression of normative values of various sorts. Hence, we must reject a *strictly* naturalistic account of this term (as well as of disease and illness).

Given the foregoing, the argument for a "weak naturalist" understanding of disability can be summarized, at the most basic level, in terms of the following syllogism:

> but the failure of the social world to accommodate to that form of embodiment by removing barriers. Various examples or folktales are employed to illustrate this insight. For example, Michael Oliver has claimed that 'An aeroplane is a mobility aid for non-flyers in exactly the same way as a wheelchair is a mobility aid for nonwalkers' (Oliver, 1996: 108). This sort of statement is amusing, provocative, and forces people to attend to the ways in which we take certain things for granted. But it cannot be taken seriously. Not being able to fly is not the equivalent of not being able to walk. While both areoplanes and wheelchairs enable individuals to overcome the natural restrictions of their bodies, walking is part of normal species functioning for human beings, whereas flying is not. There is no symmetry or equality between the situation of the non-flyer and the non-walker. A wheelchair is not just one travel option for a paralysed person: it is an essential facilitator (2006, pp. 50-51).

[19] See Nordenfelt (2009) for a thorough discussion of the relationship between the conditions required to be able to work professionally, on the one hand, and the concept of work disability on the other.

(1) Diseases are "natural" (in a weak sense).

(2) Disability is relevantly analogous to disease.[20]

(3) Therefore, disabilities are "natural" (in a weak sense).

Turning our focus now to the "weak normativism" side of the coin, the central point here is simply that disease, illness, and the like exist "out there," in the "real world," in a non-normative kind of way—that is to say, they are not *merely* conventional, not merely a social construction or a matter of social values. We arrive at this conclusion by noting that the pure normativist—that is, one who wants to argue that disease, disability, and so forth are *nothing but* social conventions—must discount any constraints set by nature itself. This, however, results in absurdity: to claim, for example, that blindness or deafness is nothing but a (mere) social convention, as opposed to being a condition that involves (at least in part) *not being able to see* or *not being able to hear*—constraints set by certain natural, physical conditions—would seem to stretch credulity beyond the breaking point. But of course, once we grant this, then we have moved away from a strictly normativist position toward allowing for at least *some* sort of non-normative basis for attributions of disease or disability. To be sure, this still allows for an ingression of values (perhaps many) into such determinations; the present claim is only that determinations of "disease" or "disability" are not *solely* value-laden. Thus, we end up with a position that can at one and the same time be characterized as "weak normativist" and "weak naturalist": both values *and* natural constraints (or conditions) enter into the identification of states of affairs as "disease," "illness," "disability," and the like—hence, the position is a "weak" form of both naturalism and normativism. They are, ultimately, two sides of the same coin.

The significance of this claim cannot be overstated. We do not need to worry, for present purposes, about determining the precise *extent* to which such identifications are a matter of values versus natural constraints—that is, we do not need to concern ourselves with determining the relative contributory percentages of one versus the other. Rather, the point is that since *both* values *and* nature play a role in determinations of disease, illness, and disability, *any* account that seeks to reduce such determinations to either one or the other must be false. We must, in the

---

[20] See Ch. 3 for an argument in support of this analogy.

end, reject both strict naturalism *and* strict normativism in favor of a "weak normativism-weak naturalism" combination.[21]

Connecting this argument up now with the previous section, and with the larger project in which this work is engaged, we can say, first of all, that if a purportedly "value-neutral" (non-normative) account of disease (such as Boorse's BST) turns out to be, *in fact,* inherently normative (as critics of the BST suggest), then we must inevitably turn to *some* form of normativism. And this, in turn, is all we need for present purposes: if values enter into "disease" determinations, and if disability is sufficiently analogous to disease (as we argued in Chapter 3), then values will enter into disability determinations as well.

III. ONTOLOGICAL QUESTIONS

In this part of chapter 4 we engage in an in-depth exploration of two key ontological issues related to our analysis of the concept of disability. The first ontological issue can be expressed in terms of the following question: *with respect to what (ontological) standard are "disability" attributions made?* This, in turn, encompasses the following two sub-questions:

1. Is there a "species-typical norm" with reference to which disabilities can be/are identified?; and
2. Is disability (merely) a "neutral variation"?

The second major ontological issue can be articulated in terms of the following question: *What kind of property is being predicated of (attributed to) an individual when that individual is described as being "disabled"?* This is the set of issues and sub-issues to be addressed in this part of chapter 4.

By way of preview of the themes to be developed in this part of the chapter, we observe, first of all, that the earlier argument for a combined weak naturalism/weak normativism leads us to expect that there will be both natural and non-natural (normative) aspects that enter into identifications of states of affairs as "disability"—that is, there *is* a respect in which there is a

---

[21] A further observation is in order here. In saying that "values" come into play in determinations of disease, illness, and disability—that is, that there is always a "values overlay" in such identifications—this leaves open whether the values in question are *universal* (in an Aristotelian sense, i.e., idealized notions of human flourishing) or *local* (in the sense of reflecting sociocultural values specific to a particular context). The values implicit in such identifications may be either universal or local—or both.

species-typical norm in terms of which such identifications are made; however, values of various sorts also enter into the process. Similarly, with respect to the question about predication, our argument for a combined weak naturalism/weak normativism leads us to expect that disability will, in fact, involve the predication of both intrinsic and extrinsic properties.

A. Question #1: With Respect to What (Ontological) Standard Are "Disability" Attributions Made?

1. Is there a "species-typical norm" with reference to which disabilities can be/are identified?

a. The relationship between disability and "normalcy"

(1) Regarding a "species-typical" norm

In response to the question, "is there a 'species-typical norm' with respect to which disabilities are identified?" the answer must surely be a qualified "yes." The answer is "yes" in view of the fact that, as we have argued, weak naturalism is true—our rejection of a *strictly* non-naturalist understanding of disability entails that there is at least *some* natural basis for the identification of states of affairs as disability. We are, in the end, interested only in certain "abilities"—that is, those that fall within the bounds of certain "natural" constraints—in contrast to which "disability" is then understood.

Which abilities are we interested in? We are not particularly interested in abilities that no human being has (e.g., being able to fly without mechanical assistance; being able to see ultraviolet light). We *are* interested in abilities that human beings typically *do* have (being able to see, being able to hear, being able to walk without mechanical assistance, etc.). And, the respective abilities and inabilities are in significant measure constrained by nature: human beings do not have feathered wings; therefore, the ability to fly is simply not an ability with which we concern ourselves, and we do not consider the lack of such an ability to be a "disability." It is simply an "inability" shared by all members of the species *homo sapiens.* Examples of this sort could be multiplied. The point for present purposes is simply that there *is* a naturalistic basis for determining what counts as "disability." However, since we have already rejected a *purely* naturalistic account as well, we do not need to worry about reducing *all* such determinations to an

entirely naturalistic basis (à la Boorse). Clearly, then, the argument for weak naturalism does the bulk of the philosophical work here: once naturalism, however "weak," has been established, the other conclusions—particularly those regarding the relationship between "disability," on the one hand, and a "species-typical norm" on the other—follow.

(2) Regarding the relationship between "disability" and "species-typicality"

What exactly *is* the relationship, then, between "disability" and "species-typicality"? Some "species-typical" conditions will be considered disabilities, while others will not; whether or not such conditions are considered "disabilities" is, at least in part, context-dependent. For example, being left-handed in the context of an environment designed exclusively for right-handed persons might very well constitute a "disability," even though left-handedness as such is within the "normal" statistical distribution of characteristics (or traits) for human beings. Thus, a species-typical trait (i.e., "typical" in the sense of falling within the statistically-normal range of characteristics for the species) might nevertheless count as a "disability" given certain conditions. It follows, then, that species-*atypicality* is not necessary for disability: a species-typical trait might in certain conditions be considered a disability. Moreover, not all species-atypical traits are considered disabilities—consider, for example, having type-O blood. Thus, species-atypicality is not *sufficient* for disability. Consequently, species-atypicality is neither necessary nor sufficient for disability.

To generalize: if we are working with an understanding of "normality" as being equivalent to "species-tpyical," then given the foregoing we are led to the conclusion that there is no *necessary* connection between "species-typicality"/"normality," on the one hand, and "disability," "disease," or "illness," on the other—it is, rather, a *contingent* relationship. Some further normative evaluation—e.g., condition X is disvaluable because of feature Y (beyond its statistical normality or abnormality)—will inevitably be invoked in designating a state of affairs as one of disease, illness, or disability. The upshot of this is that there is always a "values overlay" involved in such determinations—that is, characterizations of such states are not, and cannot be, exhausted by appeals to "normality" or "species-typicality" alone. In other words, the answer to

our question regarding whether or not there is a "species-typical norm" is that there *is* such a norm, but it must be characterized in terms of a *combination* of both statistical normality *and* an evaluative judgment of some sort (e.g., regarding the desirability or undesirability of a particular condition, given certain goals, relevant environment, and so forth).

2. Is disability (merely) a "neutral variation"?

As we have seen, some disability rights advocates have advanced a thesis along the following lines: if the social and/or physical (i.e., constructed as opposed to naturally occurring) environment were different, we would not be disabled; since the social-physical environment is to blame for our disability, society should be changed accordingly—and in many cases, *radically* so. In support of this thesis, some advocates of the social model of disability have argued that disability is nothing more than a "neutral" human variation, on a par with differences in eye and skin color, musical ability, and so forth (Parens & Asch, 2000a, p. 20). On this view, "disability" itself is "neutral"; the key factor that transmutes such a "neutral" feature into a "disabling" condition is the social environment in which the person who has that feature finds herself (Parens & Asch, 2000a, pp. 23-24)—thus, change the social environment and you change whether a condition amounts to a "disability." As a case in point, social model theorists often point to the "Martha's Vineyard case," in which an inordinately large deaf population was incorporated fully into the community (sign language was regularly utilized, etc.), such that the "impairment" of deafness was no longer "disabling" for the deaf population (Parens & Asch, 2000a, pp. 23-24). Based on this and other such real-life illustrations, social model theorists typically advance as their "central claim" the contention that "...so-called disabling traits are neither disabling nor 'disvaluable,' but neutral" (Parens & Asch, 2000a, pp. 23-24). This central claim is taken to have an important implication—namely, that, "in a differently constructed social environment, what are now disabling traits would become 'neutral' characteristics" like those noted above—which, of course, would militate in favor of a greater emphasis on social reform as an answer to the "problem" of disability (Parens & Asch, 2000a, p. 23).

In assessing this claim, there are a number of important critical questions that can be raised. Before proceeding further, however, it is critically important to note in this context that the

question we are addressing here is an *ontological* one—that is, *ontologically* speaking, does it make sense to say that disability is *merely* a "neutral variation? The significance of this caveat will become apparent later in this subsection.

Turning now to our critical analysis, one might begin by questioning whether this sort of account, and the illustration used in support of it (the Martha's Vineyard case), succeeds in showing a trait such as deafness to be nothing more than a "neutral variation." To be sure, the social environment on Martha's Vineyard was arranged in such a way as to be conducive to deaf persons' being able to participate in the life of the community; it surely does not follow from that fact, however, that they were not *disabled.* One might plausibly insist that because they were still *unable to hear,* they remained "disabled," though the effects of such disablement may have been mitigated significantly through amenable social institutions and practices.[22] We can thus raise serious questions regarding the alleged "non-disabled" state of the deaf population in the Martha's Vineyard example. Which is to say, in other words, that everything will turn on how one conceptualizes disability—and *that* is a matter for further debate.

Of course, this difficulty has not gone unnoticed by disability scholars, so it is important to proceed carefully in our analysis and critique of the relevant literature. Many advocates of the social model, for example, do acknowledge that there is a sense in which "disability" is *not* a strictly "neutral" variation.[23] Realistically speaking, as Parens and Asch acknowledge, it cannot be denied that "disabling traits—departures from species-typical functioning—foreclose some options, [and] that some disabilities foreclose more options than others" (Parens and Asch, 2000a, p. 24). Thus, a child who suffers from profound mental retardation may not be able to read and understand an abstruse philosophy text or balance a checkbook.[24] In that sense, then, the disabling trait is quite "real"—certain options may be foreclosed to the individual who has the

---

[22] Cf. Hans S. Reinders' "blind Robinson Crusoe" thought experiment, discussed in chapter 2 of this work.

[23] Cf. the discussion of the "constrained" vs. "unconstrained" social models, in Chapter 1.

[24] There is, of course, a rather wide range of functional limitation associated with various disabilities, including developmental disabilities such as mental retardation, so generalizations of this sort should be taken as merely illustrative or suggestive. Further, even among those disabilities having a biological or physiological substrate (whether *all* disabilities have such a substrate is a separate question that I will not pursue here), there can be significant variation in their effects on functionality—consider, for example, the differences between deafness, (mild) depression, and an amputated limb.

disability, and that foreclosure of options may not be assimilable to the influence of the social environment.[25] In this way, the disability is "inherent in the characteristic itself" rather than a mere social construction. At the same time, however, advocates of this view insist that by focusing attention on options and possibilities that are *foreclosed* by a given "disabling trait," we unduly minimize the myriad ways in which a society can make it possible for "people with disabilities to enjoy alternative modes of those same activities"—e.g., ways that the child with mental retardation might be able to enjoy aesthetic and intellectual activities apart from reading philosophy—and also tend to obscure the existence of the "nearly infinite range" of opportunities and possibilities that remain open to persons with disabilities (Parens and Asch, 2000a, pp. 24-26).

Having issued this caveat, however, it cannot be denied that members of the "disability community" themselves often speak in different—and conflicting—ways regarding whether or not disability is a "neutral" characteristic, sometimes acknowledging a "biological reality," at other times speaking as if disability were literally "neutral." Thus, on the one hand, Adrienne Asch argues that "[t]he inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options" (Asch, 1989, p. 73, cited in Parens & Asch, 2000a, p. 23). By contrast, Deborah Kent, a blind activist, relates autobiographically that she "premised [her] life on the conviction that blindness was a neutral characteristic" (cited in Parens & Asch, 2000a, p. 23). In this latter mode of discourse (represented by Kent), "the disability community argument is often that... these so-called disabling traits are not, to coin a term, 'disvaluable' in themselves; they are disvaluable because of the way they are socially constructed" (Parens & Asch, 2000a, p. 23).

Here, we might raise critical concerns at two levels. First, at the level of specific examples, the claim that blindness is a "neutral" trait can certainly be challenged. As Asch and Parens put it,

> [a]s a descriptive claim, it is not reasonable to say that the trait of blindness is normal. Statistically speaking, it is not. Also, as an evaluative claim, insofar as the trait can make

[25] That is to say, the "disabling trait" is a real, constitutive trait of the individual that does not change in its constitution or function in different environments.

> it impossible to enjoy some wonderful opportunities, it does not seem reasonable to say that the trait is neutral. The trait may indeed seem neutral and insignificant when viewed in the context of the whole person; but that is a claim about the person, not the trait.... the descriptive and evaluative claims about the trait do not bear a necessary logical relation to evaluative claims about the person who bears it. As an evaluative or moral claim about the person, it makes perfect sense to say that a person who is blind is normal; she is normal in the sense that she deserves the normal, usual, equal respect that all human beings deserve (Parens & Asch, 2000a, p. 27).

Here, Parens and Asch helpfully draw our attention to two important distinctions—namely, (1) that between *descriptive* and *evaluative* claims, and (2) that between the *person* and the *trait*—rightly reminding us that descriptive claims do not necessarily entail evaluative claims, and that neither descriptive nor evaluative claims about a *trait* necessarily entail descriptive or evaluative claims about the *person* who has that trait. In drawing our attention to these distinctions, Parens and Asch effectively undercut at least some of the rationale for opposing "medical" descriptions or explanations of disability.

Further reasons for questioning the opposition to "medical" descriptions or explanations of disability are provided by bioethicist Bonnie Steinbock (2000). As we have observed, the social model of disability is driven in large part by the "forms of variation" argument, the core of which Steinbock identifies as follows:[26]

> The claim that disabilities are just forms of variation among others presumably means something like the following: most people get around by using their legs to walk, but some people use a wheelchair. The latter is not worse, just different. Most people communicate by hearing voices and speaking, but some people use sign language to communicate. The use of sign language is not worse, just different (Steinbock, 2000, p. 110).

For Steinbock, this is a "surprising" claim: we do not, she points out, say the same thing about other "deviations from normal functioning" (e.g., laryngitis). What is it that could make, say,

---

[26] See Steinbock (2000), pp. 110-113 for this discussion.

blindness a "form of variation" where laryngitis is not? In an effort to answer this question, Steinbock considers the possibility that the "forms of variation" argument trades on the distinction between illness and disability—i.e., that "it is possible to have a disability (be mentally retarded, blind, deaf, paralyzed) and be perfectly healthy," whereas one cannot, for example, have laryngitis and simultaneously be "perfectly healthy." Being blind, then, would be a "form of variation" whereas having laryngitis would not (Steinbock, 2000, p. 111).

But, Steinbock counters, the fact that one can have a "disability" and also not be in "ill health" does nothing to show that disabling conditions "are not medical, much less that they are just forms of variation" (Steinbock, 2000, p. 111). For example, in the case of high blood pressure that is controlled by medication, we would not be inclined to say that there is *no medical problem* and that high blood pressure is nothing more than a "form of variation." Rather, we would be inclined to say that having a long-term medical condition and "being healthy" are compatible with one another. If this is the case, then resting the "forms of variation" argument on the distinction between "illness" and "disability" will not be sufficient to establish the argument's conclusion. Steinbock puts the point this way:

> You can be healthy and have high blood pressure, which you control with medication. Why is there no group insisting that their blood pressure is just a form of variation, indeed, that the very term 'high' blood pressure is offensive? Clearly, it is because people with high blood pressure are not usually subjected to discrimination and stigmatization. This suggests that the problem with the 'medical model' is not that it sees a health problem where none exists, but rather the problem lies in the discrimination and stigmatization that people with disabilities have experienced over the centuries. Discrimination against people with disabilities is inarguably bad. It is a separate question whether the medical model in general, and prenatal testing and selective abortion in particular, either lead to or manifest discrimination against people with disabilities....[27]

[27] Although this is not the primary focus of the present work, concerns regarding the practical implications of adopting one model of disability versus the other—especially the issues surrounding prenatal genetic testing and selective abortion for disability—obviously (and, perhaps, inevitably) loom large in the background of the conceptual and theoretical discussions.

Steinbock goes on to argue that "variation" can only be understood with reference to a "norm." Thus, for example, "[a]ll human groups speak some language, but no language is 'the norm.' By contrast, a human being beyond infancy who cannot speak any language is a deviation from the norm; he or she lacks normal human abilities" (Steinbock, 2000, p. 111). References to such a "norm" are, according to Steinbock, useful tools, or conventions, for determining when, for example, one is sick and in need of medical attention. Reference to a "norm" also provides useful markers for various stages of physiological development. There is, in other words, no reason why reference to a "norm" or that which is "normal" ought, *ipso facto*, to be objectionable.

The driving force behind the concern with referring to that which is "normal" in order to define disability as something more than just a "form of variation" seems to be, on Steinbock's assessment, the desire to resist the tendency to view disability as being "inherently bad, inherently disadvantageous, inherently a problem" (Steinbock, 2000, p. 112). While understandable, Steinbock counters, this concern tends to blur the distinction between that which is by itself a "disadvantage" versus that which is a "disadvantage on balance." Thus, by way of illustration, we seem able to make a distinction between a musician who has polio, and who therefore is disadvantaged in the sense of having certain career paths foreclosed (such as being a mountain climber or professional boxer) and that musician having a life that is "disadvantaged on balance." While we may, for example, acknowledge that Itzhak Perlman (the musician in Steinbock's illustration) is not "disadvantaged on balance," we seem nevertheless willing to say that the pain and discomfort caused by his polio constitutes, taken by itself, a "disadvantage" to Perlman. Our capacity to make these sorts of fine distinctions, Steinbock argues, alleviates the worry that seems to motivate the "forms of variation" argument: we can recognize the "disadvantage" of having a disability, while yet acknowledging the overall value of a life in which one has a disability.

There are, Steinbock notes, unusual circumstances in which having a disability might confer an "advantage" on the person who has it—as, for example, when a blind person is exempted from military duty. What is important here is that "[t]he fact that a disability can be

---

For discussion of some of the practical implications of disability models and categorizations, see chapters 5 and 6 of this work.

under unusual circumstances advantageous is consistent with its being ordinarily a disadvantage" (Steinbock, 2000, p. 113). However, even under more ordinary circumstances, disability may be seen as conferring an advantage of some sort: a deaf person, for example, may develop heightened abilities of concentration due to a lack of aural distractions. Still, despite these instances in which certain advantages might accrue to one who has a disability, the overall reality, Steinbock contends, is that "disabilities are not generally advantageous, not something to be hoped for; indeed, they are to be avoided, if possible. They are not merely neutral forms of variation" (Steinbock, 2000, p. 113).[28]

As a brief aside, we can connect this discussion of disability as a neutral "form of variation" with our earlier discussion of the three different domains of explanation or concern—i.e., ontological/medical-scientific, non-moral normative, and moral normative. In order to make this connection, we need to recall the distinctions, brought out in the discussion above, between (a) descriptive and evaluative claims, and (b) being a "disadvantage" *simpliciter* versus being a "disadvantage on balance." With these distinctions in mind, one might say, e.g., that a disability constitutes a "disadvantage" when viewed from a strictly medical-scientific point of view (in terms of statistically-relevant levels of functioning), and/or from a non-moral normative standpoint (when compared, for example, with ideals of form and function), yet nevertheless maintain that, from a moral normative point of view, the individual in question is not (or *ought* not to be) "disadvantaged on balance," given other traits possessed by the individual and/or given various (appropriate) social responses to the individual's anatomical/physiological limitations.[29] Distinguishing between these different areas of explanation/concern may thus help to preserve the value of each of the respective "models," while buttressing against unwarranted inferences from, e.g., descriptive claims about a trait to evaluative claims about the overall value of a life featuring that trait.

a. A note of clarification regarding the question

[28] Of course, even if we accept Steinbock's conclusion, we may still note that the question of *how* disabilities are to be "avoided" remains an open one. *That* issue, however, is not one that will be addressed in this work. For one recent discussion of this issue, see Purdy (2009).

[29] This might also yield helpful prescriptive imperatives: the practical question would be, given the disadvantages in the first two domains, what is needed in the third (social) domain to make it so that the individual is not "disadvantaged on balance," or at least that such disadvantage is minimized to the extent possible?

To avoid confusion here, it should be emphasized again that in asking the question, "is disability a 'neutral variation'?" we are asking the question at the *ontological* level—that is, does it make sense *ontologically* to speak of disability as a (mere) "neutral variation"? The reader will recall that in chapter 3 we suggested that, on a biopsychosocial approach to disability, each of the various individual conceptualizations of disability—i.e., disability as defect, tragedy, neutral variation, and form of culture—are (in some sense or other) correct, but at a different level of explanation. It may seem that we are contradicting ourselves here: where earlier we claimed that disability *is* a "neutral variation," now it seems we are denying that claim. However, what we are arguing in the present context is that, *ontologically,* it does not make sense to speak of disability as a neutral variation. This still leaves open the possibility that there is some other sense in which it *does* make sense to speak of disability in this way. Thus, it may turn out that, for example, at the social level of explanation, it *does* make sense to speak of disability as a neutral variation. If this is correct, then there is no contradiction in saying that disability *is not* a "neutral variation" at one level—the biological/ontological—while affirming a sense in which, at a different level of explanation—e.g., the social/moral normative level—it *is* a "neutral variation."

In light of the foregoing, then, the "neutral variation" view will be presumptively suspect *as an ontological claim.* Ontologically, disability cannot plausibly be construed as a neutral variation. But this still leaves open the possibility that, at one of other levels of explanation—e.g., the *psychological* or *social* levels—it is (or can be understood as) a "neutral variation." The point, in short, is that as an *ontological* claim, the neutral variation thesis makes no sense; but, as a descriptive claim about the lived reality of disability, at the psychological and/or social levels of explanation, it may very well make sense to speak of disability in this way. We will therefore proceed on the assumption that it is, at the very least, an "open question" as to whether or not the neutral variation makes sense at either or both of those other levels of explanation.

B. Question #2: What Kind of Property Is Being Predicated of (Attributed To) an Individual When That Individual Is Described As Being "Disabled"?

1. What does it mean to characterize an individual as "disabled"?

When approaching the question "what does it mean to characterize a person as 'disabled'?" we very quickly run into the phenomenon that people do not want to be identified with one or more of their characteristics that might be deemed to be negative. Thus, they will resist the label "disabled," or at least seek to diminish the force of that characterization. (Note, for example, the preference, in some circles, for "differently-abled" language over against the "disabled" label.)

It turns out, however, that utilizing the label of "diseased" or "disabled" can, in certain contexts, be very useful. For example, "John is a diabetic" can be useful if what we are interested in is knowing how to treat John medically. We may, for example, want to make sure we have plenty of insulin on hand, especially if we will be going on a long road trip with John.

The issue here is one of *salience*—which features are relevant to a given context or objective? Salience is thus context-dependent. When different features are salient for different purposes, different labels may be appropriate (or inappropriate). Consider, for example, the following locutions:

A	B
"John is a felon."	"John committed a felony."
"He is a convict."	"He has been convicted."
"He is a diabetic."	"He has diabetes."

What is the difference between saying "John is a diabetic" versus "John has diabetes"? Strictly speaking, both locutions express the same basic idea—namely, the idea that a given individual (named John) has a condition we call diabetes. The difference here seems to be that the former ("John is a diabetic") is a more all-encompassing characterization than the latter ("John has diabetes," or "John has been diagnosed with diabetes"). Compare these statements with "John is a felon" and "John committed a felony"; in each case, the former locution seems to characterize the entire person in terms of one feature (being a felon, being a diabetic) whereas the latter appears to put some distance between the individual and that one feature (having committed a felony, having been diagnosed as having diabetes). We might say something similar about all the locutions given above: those in the "A" column appear to absorb the individual's identity into the one feature under consideration ("felon," "convict," "diabetic"), whereas the latter appears to discount or minimize the negative feature in question. (It is worth noting, too, that this is rarely

done with respect to features that are regarded as being *positive*—would John prefer that people say "John has exhibited traits characteristic of a genius" rather than "John is a genius"?)

Why, then, do people worry about being characterized as "disabled"? In large measure, this would seem to be because they do not want to be absorbed into a particular role identity; they do not want one of their characteristics to be taken as representative of their entire person.[30] The framers of the ICIDH were sensitive to this worry, and expressed it thus:

> In attempting to apply the concept of disability, there is a need for caution in how the ideas are expressed. By concentrating on activities, disability is concerned with what happens – the practical – in a relatively neutral way, rather than with the absolute or ideal and any judgments that may attach thereto. To say that someone *has a disability* is to preserve neutrality, nuances in regard to his potential still being possible. However, statements phrased in terms of being rather than having tend to be more categorical and disadvantageous. Thus to say that someone *is disabled,* as if this were an adequate description of that individual, is to risk being dismissive and invoking stigma (WHO, 1980, p. 28).

The concern about the potentially stigmatizing effect of the designation "disabled" can be seen most prominently in the heated debate over prenatal testing and selective termination on the basis of disability. For example, in an article entitled "Where is the Sin in Synecdoche? Prenatal Testing and the Parent-Child Relationship" (2005), Adrienne Asch and David Wasserman argue that in at least some cases, prenatal testing for disability, when accompanied by a decision to abort on the basis of a finding of disability, commits the "sin of synecdoche." When using the term "synecdoche," Asch and Wasserman have in mind "not the literary device, in which the part stands for the whole, but the characteristic response to a stigmatized trait in which the part obscures or effaces the whole" (2005, p. 173). The "sin of synecdoche," in turn, involves "the uncritical reliance on a stigma-driven inference from a single feature to a whole future life" (2005, p. 181). In this context, the "sin of synecdoche" is

---

[30] See Asch and Wasserman (2005) for a discussion of this concern in the context of prenatal genetic testing coupled with abortion on the basis of disability.

> to allow a single known characteristic of the future child so to overwhelm and negate all other hoped-for attributes that the prospective parents no longer desire the coming-into-being of that child. The sway exercised by that single characteristic is not accidental or idiosyncratic—it is the sadly predictable effect of stigma 'spoiling the identity' (Goffman, 1963) of the future child in the most radical possible way, by precluding him from ever forming an identity in which the impairment might play only a slight or negligible role. In responding to that characteristic as they do, parents who test and abort for an impairment ratify and perpetuate its stigmatization, however unwittingly or reluctantly. Synecdoche is thus a sin about which other people—people stigmatized by possession of the same impairment—have special standing to complain (2005, p. 182).

Clearly, then, the chief worry regarding being labeled as "disabled" is the potential for resulting stigma and discrimination. Still, as we noted above, there can also be certain contexts in which when people might *want* to so labeled—as, for example, when that designation will qualify them for certain desired benefits. Being characterized as "disabled" can be useful, just as it can be useful to be labeled "diseased" or "ill." Being deemed "disabled" can, for example, make one eligible to obtain a disabled parking placard and to receive special parking privileges. Similarly, being deemed "diseased" or "ill" might have the effect of rendering one exempt from a military draft, or (more mundanely) might constitute the basis for exemption from work or other social responsibilities.

At first blush, *both* sets of interests and concerns would appear to be legitimate. But then we are faced with a number of questions: do these interests and concerns conflict with one another? If so, how? And can those conflicts be resolved? By way of an initial foray into answering these questions, we note, first of all, that what seems to be at issue is the underlying *purpose for* or *function of* a given characterization. Is the characterization made for instrumental purposes (e.g., to render one eligible for certain government assistance programs)? Is it made in order to reduce an individual's identity to a specific feature—what we might term an "essentializing" function? Is it made with the aim of stigmatizing the person so characterized (as, e.g., might be the case in certain racially-motivated characterizations)?

In short, we can identify at least three different functions of characterizations generally, and of "disability" characterizations in particular—namely, (1) instrumental, (2) essentializing, and (3) stigmatizing. The significance of this is as follows: *the use of a characterizing label (as in "disabled") for one purpose/function need not entail use of that label for another function.* Thus, one might employ a label such as "disabled" for instrumental purposes, without intending that the label perform an essentializing or stigmatizing function as well.

2. The "neutral variation" view and property attribution[31]

The foregoing discussions serve to highlight some of the key underlying ontological issues involved in discussions of the concept of disability. One salient point to note in this context is that the "neutral variation" argument illustrates how an "extreme"—i.e., unconstrained—social model of disability appears to deny any anatomical or physiological reality to disability, and instead treats it as a purely social phenomenon.[32] To put the idea in the language of predication, 'disabled' is an extrinsic predication (i.e., something we say of a thing but which does not refer directly to a constitutive property of that thing) without an ontological foundation in things: 'disabled' is something we *say of* someone, but there is no intrinsic property of that individual that grounds and therefore justifies the predication—that is, there is nothing *present in* the individual to warrant the predication. Instead, 'disabled' has as its referent unjust social beliefs and judgments, and attitudes and practices based on them. But there is in fact no foundation for this predication in the world, so it can and should be dismissed.

These thoughts can be developed further, to help elucidate the central claims being made by the medical and social models, respectively. (Again, with the caveat that when speaking of *the* social model or *the* medical model, the focus is on the more "extreme" versions of each, with full acknowledgement of gradations in-between the extremes.) In chapter 3 we suggested that Engel's biopsychosocial model of health and disease can be employed fruitfully in the context of an analysis of disability. Along these lines, the extreme social model denies the "bio" component and treats disability as strictly "psychosocial," or perhaps even "social" only. However,

---

[31] I am indebted to Laurence B. McCullough for suggesting the line of reasoning presented in this subsection, and for providing me with some of the language used here.

[32] As the reader will recall, the unconstrained social model theorist casts both impairment and disability as thoroughly conventional, that is, as social constructions.

according to the social model, there is still something very *real* going on here—namely, a loss of social equality. Attribution of a loss of social equality is an extrinsic predication with respect to the individual concerned. Consider, for example, the case of curb cuts in sidewalks. People who are capable of independent ambulation can get from point A to point B in an area with sidewalks and streets because they encounter no obstacle to stepping up to or over curbs. People in wheelchairs do encounter such obstacles and cannot get from point A to point B; therefore, they lose equality with respect to mobility. They lose such equality, not primarily because they have to use a wheelchair, but because there are no curb cuts. Thus, they experience a *real* loss of equality, but their lack of ability to ambulate independently is not the primary cause. On this reading, the social model takes the ontological view that disability means that an individual has experienced a real loss—i.e., a loss of equality, a loss caused by social attitudes, etc., not by any intrinsic property of the individual. In this way, 'disabled' also functions as an intrinsic predication, not of the individual but of a society that is unjust—that is to say, the referent of 'disabled' is in fact a feature intrinsic to a society, namely, its unjust attitudes and practices. This allows an entailment from predicating 'disabled' of an individual to a judgment that a society is unjust, because such injustice is analytic to the concept of disability. In this case, the locution "X is disabled" means "X has experienced a loss of social equality, as a result of society's unjust attitudes/practices."

By contrast, the medical model also understands disability to involve real loss, but of anatomy (bodily structure) or physiology (bodily function), which from a medical perspective are the only two domains of biological loss. Here, the "bio" component of a biopsychosocial account of disability is back in the picture, and is in the foreground. Still, it is important to emphasize that one need not subscribe to a strictly reductionist medical model, one that leaves the "psychosocial" entirely out of the picture. Critics of the medical model frequently assume that it *must* be reductionist, i.e., that it must incorporate only the "bio" and not also the "psychosocial." But, of course, a robust medical model of disability need not entail such a reductionistic account;[33] instead, a medical model of disability could cash out 'disability' in terms of a significant

[33] In this regard, as Shakespeare et al. (2006, p. 1103) point out,

loss of anatomy or physiology, where 'significant' means that important human activities are limited, e.g., activities of daily living, social life, employment, participation in the community's political life, etc.—which, in turn, reintroduces "psychosocial" concerns into the picture. On this sort of account, the non-moral normative judgment (where "non-moral" is meant in the sense of "a good state of affairs" versus "a bad state of affairs") is that these psychosocial sequelae limit human beings in what they can do and who they can be and therefore the limitation should be addressed. Evidence-based medicine focuses on the "bio" component because for this component the evidence (e.g., that successful kidney transplantation is less limiting biopsychosocially than is long-term hemodialysis) is generally more reliable; this renders the "bio" component most *salient* to the medical context, and therefore the primary focus of attention. It should be noted, too, that this account explains why there is no (necessary) entailment relationship between a medical-model predication of 'disabled,' when it is clinically justified, and moral normative judgments: the entailment is, rather, to a set of *non-moral normative* judgments (i.e., judgments regarding psychosocial sequelae). Here, then, one of the things being attributed when we say "x is disabled" is a *loss* of a certain sort—but the loss in question (social equality, anatomy, etc.) will be different depending on the model of disability (social, medical, etc.) in which the attribution is embedded.

There is, in summary, a serious *ontological* difference between the social model—'disabled' refers to an ethically unacceptable loss of social equality, making moral normative values an essential component of the social model—and the medical model, where 'disabled' refers to a loss of anatomy or physiology that significantly limits human beings in what they can do and who they can be, which is unacceptable from a non-moral normative perspective.[34] In addition, for the social model 'disabled' is an extrinsic predication (something we say of an individual) that has no foundation in that individual's intrinsic or constitutive properties and refers to unjust attitudes and practices and therefore is an ethically illegitimate predication. Non-moral

---

> [o]pponents of the 'medical model' have created a straw man that stands for medicalization, prejudice, and the devaluing of disabled people. It is difficult to find any authors who espouse such a 'medical model' or deny the importance of social barriers and discrimination in the lives of disabled people.

[34] There is thus in both models an ingression of normative values, but of different kinds (moral vs. non-moral).

normative values appear to play no essential or significant role. For the medical model, by contrast, 'disabled' is an intrinsic predication, referring to the constitutive property of anatomic or physiologic loss, about which a non-moral normative judgment is made that disabilities are abnormal and therefore should be ameliorated and, when possible, fully corrected.[35] Moral normative values appear to play no essential or necessary role, contrary to what some critics of the medical model claim.

In light of this analysis, it is clear that the work done earlier in this project—specifically, taking up the dispute between the social and medical models of disability for the purpose of analyzing that dispute closely and critically—laid the foundation for the exploration, here in this chapter, of the ontology of disability, which in turn allows us to draw a number of further conclusions regarding the adequacy of the models as they are typically characterized in the literature. For one thing, a social model that accepts real loss of equality but rejects any real loss of anatomy or physiology (what we have here called the "unconstrained social model") is troubling, because the latter claim seems to be plainly false. Moreover, since (as we noted earlier) disabilities range along a continuum of biological, physiological, psychological, social, and other dimensions, any adequate account of disability must encompass that range of dimensions. Hence, a model that denies *any* of these dimensions will be incomplete at best.

A further upshot of this discussion is to provide yet more warrant for the claim that we need to move *beyond* the "models" debate if we are to arrive at a satisfactory account of the notion of disability. One might initially be tempted to claim that the medical and social models are "compatible" with one another, in the sense that the strengths of one model correct, or make up for, the weaknesses of the other, so that they "balance out" in the end. Yet this does not seem quite right. To take but one example: as suggested above, the social model's denial of intrinsic

---

[35] An objection might be raised here to the effect that in saying that X is "abnormal and therefore should be ameliorated/corrected," this places *value* on the "normal"—which would in itself be a controversial normative stance. If this objection is valid, then it could be that the judgment under consideration here in fact spills over into the "moral normative" realm—namely, by involving a judgment that the abnormal *ought* to be alleviated/corrected. But this would not seem to be fatal to the analysis presented in this paragraph, for the central contrast here is between what kinds of values play a *necessary* or *essential* role in each of the respective models (medical versus social). Presumably, it might be possible for a model to encompass *both* normative *and* non-normative values and judgments. Here again, we see the recurrence of the "both-and" theme we have developed throughout this work.

predication in the attribution of 'disabled' regarding an individual is not plausible. The medical model, by contrast, does acknowledge this sort of intrinsic predication, but fails to acknowledge the *extrinsic* predication (i.e., external social and environmental factors) to which the social model points. So, the situation is not that one model *corrects for*, or *makes up for* the weaknesses of, the other; the reality, instead, is that *both* models fail adequately to capture a necessary component of the disability phenomenon—a flaw that, arguably, is corrected by the more adequate and comprehensive account developed in this work.

IV. IMPLICATIONS FOR UNDERSTANDING 'IMPAIRMENT' AND 'DISABILITY'

In this final part of the chapter, we want to pull together and to build upon all that has come before, in an effort to distill the various discussions down to a number of key elements that will help to fill out our developing "picture" of disability, characterized in terms of a biopsychosocial approach. Before proceeding further, however, we first need to pause briefly to highlight two important distinctions which individually and collectively help to disambiguate the notion of "disability" from two other, closely-related but distinct phenomena—namely, inability and illness. We will take each of these distinctions in turn; their significance to our larger project will become apparent shortly.

A. Two Important Distinctions

1. Disability versus Inability

First, there is the distinction between "disability" and "inability." For example, the lack of ability to speak twenty languages is best construed as an *inability* rather than a *disability*: because we do not generally expect human beings to be able to speak twenty languages, we would not typically consider this lack to be a *disability.* On the other hand, a *disability* does not necessarily entail an *inability*. For example, a disability with respect to walking does not entail an *inability* with respect to mobility: if one has a wheelchair at one's disposal, then mobility remains feasible despite a walking-related disability.[36]

2. Disability versus Illness

[36] Edwards (1997) discusses some of these distinctions en route to arguing for "Dismantling the Disability/Handicap Distinction."

Next, let us consider the important but often-overlooked distinction between *disability* and *illness.* As Silvers puts the distinction, "[w]e cannot be both well and ill at the same time, but we can be both perfectly well and yet disabled" (Silvers, 1998, p. 77). According to Silvers, "...it is odd to describe a strong and flourishing baby as in ill health just because the child is born deaf" (Silvers, 1998, p. 77). This is not to deny, Silvers acknowledges, that there are disadvantages associated with deafness; it is, however, to deny the claim that deafness necessarily entails the reduction in quality of life implied (or typically taken to be implied) by the term 'illness.' In this way, she says, "[t]he social model of disability disconnects our conceptualizations of disability from illness and pain so as to ensure that no judgment about the lives of people with disabilities is distorted by uncritical assumptions about their suffering" (Silvers, 1998, p. 76).

Silvers goes on to offer the following argument in support of the distinction between disability and illness. First, medical treatment is neither needed for disability, nor does it successfully alleviate it, whereas medical treatment *is* indicated for illness and *does* successfully alleviate it.[37] Second, illness is typically "globally incapacitating" in a way that disability is not.[38] Therefore, despite the fact that illness and disability are often linked empirically, they should not be identified with one another (Silvers, 1998, pp. 77-78).[39]

Further, Silvers says, we can also see that illness and disability are distinct by way of a consideration of the nature of the so-called "sick role." Citing Amundson (1992, p. 114, 118), she notes that "the 'sick' role is a kind of social stepping or stopping out that is inappropriate for someone with no illness but only a disability" (Silvers, pp. 78-79). Being identified as sick or ill brings with it certain social disadvantages—even stigma—that seem inappropriate in the case of

---

[37] "...persons with paradigmatic disabilities... neither require nor are improved by medical treatment, differentiating them from people suffering from illnesses.... there are no medicines for disability. This observation furnishes another reason to think that the remedy for the 'disability problem' lies in social reform, not in biochemical intervention" (Silvers, 1998, pp. 77-78).

[38] "In contrast to the specificity of functional limitation that characterizes disability, an individual who is ill usually is more globally incapacitated" (Silvers, 1998, pp. 77-78).

[39] "It is informative to investigate how diseases contribute to disabilities, and there is reason to think that being disabled in a hostile environment increases one's exposure to becoming diseased. All of this suggests that disability may be linked empirically to illness but should not be identified with it" (Silvers, 1998, pp. 77-78).

disability (Silvers, pp. 78-79). In short, on Silvers' account, though often *associated* with disability, illness is neither *necessary* nor *sufficient* for disability.[40]

---

[40] As Silvers puts it,

> [T]he distinction between disability and illness, as I limn it, acknowledges that disability often is a sequela of illness and also that illness, especially chronic illness, can itself be disabling.... Nevertheless, being ill, even chronically ill, is neither a necessary condition nor decisive evidence that an individual has a disability (Silvers, 1998, pp. 79-80).

By way of a brief critical assessment of Silver's arguments here, we might make several comments. First, one might wonder exactly why it is that Silvers says it would be "odd to describe a strong and flourishing baby as in ill health just because the child is born deaf." Clearly, what Silvers has in mind is the idea that illness involves a degree of systemic incapacitation not necessarily attendant upon the presence of a disability (as in the quotation above). In the example under consideration here, aside from her deafness the baby is otherwise "strong and flourishing" by virtue of the fact that all her vital organs are functioning normally; sensory deficit does not affect vital organ functioning and thus has no implications for the infant's well-being as such. (I owe the formulation of this last point to Laurence B. McCullough.) From this perspective, Silver's comment makes perfect sense, and is surely correct: indeed, having a disability does not (necessarily) entail systemic incapacitation of the sort typically associated with "being ill." On the other hand, in ordinary language contexts, when people inquire as to whether a newborn baby is "healthy," they typically have in mind not only the absence of disease and illness, but also of disability; when there is a disability of one sort or another, people are often hesitant to speak of that baby as "perfectly healthy." From *this* perspective, it may *not* be so "odd" to refer to a baby who is born deaf as being, in some sense, in "ill health." At the very least, some further conceptual clarity would be helpful at this point.

Second, it is not entirely clear that the medical model does in fact make "uncritical assumptions" about the "suffering" experienced by persons who have disabilities—or, at least, it is not clear that such assumptions *necessarily* undergird the medical model, as Silvers appears to imply. (In this respect, as Laurence B. McCullough pointed out to me in personal conversation, this charge against the medical model represents an unwarranted generalization). Here again, the issue comes down to a question of what the "medical model" is taken to offer: if, for example, it is taken simply to offer an explanation of the presence of disability in medical-scientific terms (the "Why?" question)—*and no more than this*—then there would seem to be plenty of conceptual room remaining to effect the sort of "disconnect" of "conceptualizations of disability from illness and pain" for which Silvers rightly calls. The point, in other words, is that the medical model can explain the presence of disability in medical terms without assuming a *necessary* connection between disability, on the one hand, and pain/illness on the other. So long as the connection between the two is contingent, rather than necessary, the "disconnect" for which Silvers rightly calls can still be effected.

Third, several of Silver's claims made in support of the distinction between "disability" and "illness" seem patently false. For example, she says that "persons with paradigmatic disabilities... neither require nor are improved by medical treatment." But surely this is too strong a claim: many "disabling" conditions can be improved, if not cured altogether, by way of medical treatment. (Witness, for example, the many "medical" treatments available to those with spinal cord injuries and progressive neurological disorders.) Similarly, while it may not be possible to eliminate altogether a given disability by way of medicines, to say that "there are no medicines for disability" ignores the fact that many of the *symptoms* (e.g., pain, muscle spasticity, etc.) associated with disabilities can in fact be treated by means of medication. Two general thoughts come to mind here. First, if these claims were correct—that is, if it really *were* true that persons with disabilities "neither require nor are improved by medical treatment," and that "there are no medicines for disability"—then it would be difficult to see why disability rights activists should have any concerns whatsoever about the so-called medical model. Indeed, rather than being problematic, the medical model would simply be irrelevant; since there would be no way of "acting on" the prescriptions of the medical model, there would in turn be no reason for concern that acting on

B. On the Necessary and Sufficient Conditions for Impairment and Disability

We now want to draw upon our earlier discussions to see if we can identify at least some of the key variables that contribute to, or enter into, the creation of states of affairs that are ultimately labeled "disability." Importantly, this is not intended as an exhaustive list—indeed, further scholarship may, over time, reveal heretofore unrecognized factors that contribute to bringing about these states of affairs. Our immediate objective is simply to see if our discussion thus far provides us with resources to identify at least *some* of these key factors.

To that end, we can advance the following general conclusions, based on our previous conceptual explorations:

- Negatively speaking, as our earlier discussions showed, we can rule out both "species-atypicality" and "illness" as being either necessary or sufficient conditions for disability.
- Based on our earlier discussion of the kinds of predication involved in medical versus social model conceptualizations of disability, we can say that some sort of anatomical, biological, or physiological "loss" is a *necessary* (but not sufficient[41]) condition for disability.
- The foregoing discussion of the analogy between disease and disability would appear to support the claim that "being undesirable" is a necessary but not sufficient condition for disability. That is to say, just as a condition must, at minimum, be considered (generally)

---

the medical model would have deleterious consequences for those with disabilities. Second, if it is in fact the case that medical treatments *can,* in at least some cases, either cure or ameliorate disabilities and/or the symptoms associated with them, then this would constitute a *prima facie* challenge to Silvers' contention that "the remedy for the 'disability problem' lies in social reform, not in biochemical intervention." Rather than having to choose between the two, why not instead advocate for *both* "social reform" *and* biochemical intervention? At first glance, at least, it is not immediately obvious why we must accept the either-or dichotomy rather than a both-and response to the "disability problem."

All this having been said, these critical comments should not be taken as a rejection of Silvers' larger claim that there is an important distinction to be made between 'disability' and 'illness.' With *that* claim I entirely agree. Moreover, I agree with her conclusion that 'illness' is neither *necessary* nor *sufficient* for 'disability." My main worry, for present purposes, is to ensure that arguments made in support of this distinction rely upon premises that are themselves conceptually defensible. And my principal objection, in the present context, is to the implicit assumption of the necessity of an *either-or* rather than a *both-and* response to the "disability problem." With respect to both that worry and this objection, I think there is much important conceptual work remaining to be done. (We will return in Chapter 5 to a discussion of issues related to societal responses to disability.)

[41] For example, except perhaps in extreme cases, loss of body hair would not generally be considered a disability.

undesirable before we label it a "disease," so, too, a condition labeled "disability" is, all other things being equal, considered an *undesirable* state.

Additionally, as we have seen throughout, designations of states of affairs as either "disease" or "disability" will be dependent upon the relevant environment and/or goals (i.e., those of the individual and/or the larger society in which she lives).

C. Disability as a Multi-Place Predicate

Taken together, these observations suggest a potentially fruitful line of inquiry—namely, that of conceptualizing disability as involving multi-place predication. Here, the idea is that disability can be captured accurately only in terms of *multiple* variables, along something like the following lines:

> Dxyz,
>
> where D = Disability,
>
> x = an *impairment,* understood as involving an objectively real and (generally) undesirable *ontological* loss;
>
> y = the individual's goals (broadly construed to include her entire psychological state); and
>
> z = the individual's environment (broadly construed to include the naturally-occurring, built/arranged/constructed, and social environments).

This is, of course, just one example of the sort of multi-place predication account that one might devise. One could conceivably construct this sort of account in a number of different ways, with either a greater or smaller number of variables. For example, in a recent essay Christopher Boorse suggests the possibility of a "contextual" account of disability, according to which the concept of disability is "multidimensionally vague." The basic idea here is that,

> in practice, disability judgments rest on a basic predicate with three or four argument places to be filled by context. To begin with, whenever anyone is called disabled, we must ask: "Disabled from what?" Context determines an *activity*, or range of activities, from which a person is disabled: a sport, a particular job, all jobs, the ADA's "major life activity," or something else. Since every conscious person can do something, it makes no

sense to call a conscious person "disabled" *tout court*, without implicitly referring to some range of activities. Second, disability judgments are normally intended to have a practical *consequence*, prudential, moral, or legal: the person ought not be asked (or allowed) to play baseball today, or ought to get a cash income or reasonable accommodation in a workplace, public building, or parking lot. Whether or not such a consequence is part of the meaning of 'disability', writers tend to use 'disabled' as short for, as it were, 'disabled enough'. Practically, then, a disability is an inability of a certain type, severe enough to justify a certain consequence. Moreover, one must often specify the *environment* of the disability. That is why the ICF (2001, p. 15) distinguishes "capacity," a person's ability to do things in a standard environment, from "performance," his ability to do them in his current environment. So, in context,

x is disabled by impairment I

really means something like

Because x has impairment I, which significantly limits x in activities of type A in environments of type E, x deserves the consequence C

(Boorse, 2009, p. 68, italics in original).

Again, our purpose in this immediate context is not to attempt to develop a complete, *definitive* "contextual" or "multi-place predicate" account of disability, one that exhaustively accounts for all possible variables that might enter into a state of affairs to be labeled "disability." Rather, the key points to be emphasized here are two-fold. First, our conceptual explorations up to this point give us good reason for thinking that any adequate account of disability must, of necessity, include a *number* of variables, rather than attempting to reduce the explanatory account to strictly one or another factor (i.e., *only* biological/anatomical/physiological "defect," on the one hand, or *only* social attitudes and practices, on the other). Second, the "biopsychosocial" approach that we are developing in this work would appear to be well equipped to accommodate this range of explanatory features in its overall account. The next subsection is devoted to developing this idea further.

D. The BPS Approach and the Types of Predication Involved in "Impairment" and "Disability"

The primary purpose of this section is to show how the foregoing material regarding ontology helps us better to understand the types of predication involved in attributions of 'disability'—and, more generally, to gain a deeper, richer understanding of the disability phenomenon overall. In particular, we want to know the answer to the following question: When is 'disability' a predication of intrinsic constitutive properties versus a predication of judgment?

The key to answering this question is to connect the BPS approach's distinction between "levels of explanation" (biological, psychological, social), on the one hand, with the distinction between "intrinsic" and "extrinsic" property predication, on the other. The central question will then become, what type(s) of predication is/are involved at each of the levels of explanation? Or, to put the question in slightly different terms, at each level of explanation, what sort of property (intrinsic versus extrinsic) is being attributed to its referent? Speaking in the most general terms, the basic claim of the "biopsychosocial" approach is that "disability" involves the attribution of a *combination* of intrinsic *and* extrinsic properties, at different levels of explanation (biological, psychological, social). The answer to the above question, in short, will then be that the "disability" label always and inevitably involves *both* type of predication mentioned.

To make the foregoing more precise, we need to add the following important qualification. As we have seen, to attribute "disabled" of an individual is to attribute a *real loss,* of a *biological/anatomical/physiologic* sort, at the *ontological* level. As we saw earlier, the unconstrained social model's denial of the objective reality of impairment is untenable, so our account needs to include an objectively real property that is intrinsic to the individual. The attribution of '*impairment*,' then, is in this sense an attribution of an "intrinsic" property. Since *disability*, in turn, is grounded in an ontologically real impairment, it, too, involves an "intrinsic" predication at this level of explanation. This, then, is what we mean by saying that at the *ontological* level of explanation, "disability" involves the predication of an *intrinsic* feature of the individual. Importantly, however, it remains an open question as to whether other forms of loss—for example, psychological, social, etc.—are involved. The story may turn out to be very different

at the *psychological* and *social* levels of explanation. Indeed, at the *psychological* and/or *social* levels of explanation, the predication involved may be either intrinsic or extrinsic, or both.

This latter observation also allows us to nuance our previous comments regarding the "neutral variation" conceptualization of disability. We argued earlier that this view must be rejected as an *ontological* claim. As we have seen, because the neutral variation view says that all we have *just is* different traits (or functionings), that view is necessarily committed to the position that 'impairment' and 'disability' involve strictly *extrinsic* predications. On this view, one cannot refer to an impairment as being *objectively* real, ontologically speaking. But, for reasons we have discussed on numerous occasions throughout this work, that claim is untenable. Therefore, we must reject the "neutral variation" view *at the ontological level* of explanation. However, as we have just seen, the *psychological* and *social* levels of explanation may very well turn out to involve either intrinsic or extrinsic predication, or both. Consequently, the "neutral variation" view may turn out to be a viable option where those levels of explanation are in view.

A final observation is in order here. Earlier we developed an argument for a "weak normativism/weak naturalism" position vis-à-vis the concepts of health, disease, illness, and disability. We can now see how much philosophical work that position does for us. For as we can see, an acceptance of that position implies, in turn, that our predications of "impairment" and "disability" are, inevitably, guided by certain very real "natural" constraints. Consequently, these notions cannot be construed as *merely* social constructions. The significance of this, in turn, is that any theoretical approach that seeks to reduce either impairment or disability to being *only* a social construction must be false and therefore should be rejected outright.

V. CONCLUSION

This chapter has been concerned with an exploration of ontological issues as they relate to the concepts of impairment and disability. In this regard, the chapter first attended to the background theoretical issue in terms of which this exploration takes place—namely, the question of whether disability is more like a "natural kind" or an instrumental classification. Here, after setting forth the general theoretical contours of the naturalism/non-naturalism and normativism/non-normativism debates, we went on to argue for a combination of weak naturalism

and weak normativism vis-à-vis the concept of disability. Importantly, we have not attempted in this chapter to settle definitively the broader philosophical debate about "natural kinds"—such a project would take us well beyond the scope of this present work. Instead, our chief aim here has been simply to show that disability cannot plausibly be construed as *merely* an instrumental classification; in that sense, it is more like a natural kind than an instrumental classification.

This discussion of natural kinds versus instrumental classifications served as important conceptual background to the chapter's subsequent exploration of specific ontological questions regarding disability. This chapter explored two such questions in particular. First, we considered the question whether there is a "species norm" with reference to which disabilities are or can be identified. This discussion included consideration of two related sub-questions: (a) what is the relationship between "disability" and "normality" (or "normalcy")? and (b) is disability (merely) a "neutral variation"? The upshot of our discussion of these issues was to argue that there *is* such a species norm—namely, a combination of statistical normality *and* an evaluative judgment of some sort. Following on and in light of that discussion, we also advanced an argument to the conclusion that, *ontologically* speaking, disability is not plausibly conceived of as a "neutral variation."

The second major ontological question to which this chapter attended is the question of what kind of property is being attributed to an individual when we say that he or she is "disabled." After noting several purposes to which such attributions of 'disability' might be put—i.e., instrumental, essentializing, and/or stigmatizing—we went on to argue that the kind of predication involved in the attribution of 'disability' to an object is a combination of intrinsic and extrinsic predication—that is, a *relational* predicate, to borrow the language we used earlier in this work. In short, the central claim of the BPS approach with respect to predication is that 'disability' involves the attribution of a *combination* of intrinsic *and* extrinsic properties, at *different levels of explanation* (biological, psychological, social).

As with the previous chapter, we are now in a position to draw some general conclusions regarding impairment and disability, based on the work done in this chapter. Here, our explorations led us to the general conclusion that impairment and disability must be understood, ontologically speaking, in realist terms. However, it is equally clear that normative values of

various sorts do enter into the proper characterization of impairment and disability as well. Therefore, any adequate characterization of impairment and disability must incorporate *both* of these realities. Having examined specifically *ontological* issues in this chapter, the obvious next step is to consider the extent to which *normative* considerations (of both the moral and non-moral variety) enter into a proper understanding of impairment and disability. We turn to that task in Chapter 5.

Chapter 5

THE CONCEPT OF DISABILITY: MORAL AND NON-NORMATIVE ISSUES

I. INTRODUCTION

Building on the ontological account developed in chapter 4, and the account of predication that that ontological account grounds, we turn now to a consideration of moral and non-moral normative issues as they relate to the concepts of impairment and disability. Specifically, this chapter addresses the following two questions:

(1) What role should *non-moral normative* considerations be understood to play in identifications of states of affairs as "impairment" or "disability"?

(2) What role do *moral normative* considerations play in our conceptual *understanding* of impairments and disabilities, on the one hand, and in judgments regarding appropriate social *responses* to conditions so labeled, on the other?

In chapter 4, we saw that disability is not *merely* a social construction. Nevertheless, values of various sorts do enter into the identification of states of affairs that we label "impairment" and "disability." We now need to identify what sorts of values enter into such determinations; this is the major project of the first part of this chapter.[1] In this regard, the chapter identifies three distinct domains of non-moral normative values that enter in various ways into identification of states of affairs as "impairment" or "disability"—namely, (1) aesthetics; (2) cultural

[1] In this context, the chapter asks the following question: what is the extent of ingression of normative values into determinations of "impairment" and "disability"? This is, as we saw in chapter 4, the normativist/nonnormativist debate (in the philosophy of medicine) as applied to the domain of disability. In chapter 4 we introduced this debate by way of a consideration of the dialectic between Engelhardt (1996) and Boorse (1997) on the question of the value-infectedness of determinations of disease, illness, and disability. We then went on to argue for a weak naturalist/weak normativist position vis-à-vis these matters. This involves the claim, at minimum, that there is at least *some* ingression of normative values into such determinations.

If the work of Chapters 1-4—especially that of Chapter 4, where we advanced an argument for a weak naturalism/weak normativism position—has been successful, we have shown that both impairment and disability are value-laden notions. Consequently, we will not rehearse those arguments here; we will, instead, assume their correctness and go on to query, with respect to impairment and disability, with what sorts of values they are laden. To avoid confusion at this point, however—especially in light of material in chapters 1 (regarding the types of predications involved in the individual models) and 4 (regarding weak normativism as implying that all the conceptual terms are value-laden to some extent)—a word of clarification is in order. Specifically, we need to underscore the distinction between *normativity,* on the one hand, and *types of predication,* on the other, as these notions are used in this work. By "normativity," we mean the extent to which a given term is *evaluative,* in the sense of involving a comparison against a norm of some sort (whether individual, socio-cultural, etc.). So, for example to say that "impairment" is a "normative" term is to say that it is value-laden, to some extent or other, in that it involves a comparison against some normative standard. On the other hand, to say that a given model involves "intrinsic" predication with respect to impairment is to say that the model conceptualizes impairment as a feature *of the individual* (i.e., located or "present in" the individual)—whatever else we might also go on to say about whether or not, and the extent to which, it is identified with reference to some norm (individual, social, or otherwise).

theory; and (3) epistemology (in connection with judgments regarding "quality of life"), respectively.

In the first domain, that of aesthetic values, we might raise questions concerning, for example, the value (intrinsic or instrumental) of aesthetic experiences, particularly those experiences that are foreclosed by specific types of impairment—and what implications, if any, that has for judgments regarding the goodness or badness of disability as such. In the domain of cultural values, we might raise questions regarding, for example, the possibility and/or coherence of referring to a "disability culture," or to a culture associated with a specific impairment (e.g., deafness—as in "Deaf culture"). Finally, in the epistemic domain, we might raise questions having to do with epistemic standing and/or privilege (e.g., do persons with disabilities enjoy a unique epistemic privilege when it comes to making judgments about the "quality" of their lives?). It is worth noting in this context that aesthetic, cultural, and epistemic issues are frequently intertwined with one another in complex ways. Thus, for example, aesthetic judgments regarding the value of different kinds of experiences necessarily involve questions of epistemic standing: *whose* judgments and *which* perspective(s) will be given priority, especially when different judgments conflict? There is thus an important interplay between these domains of value.

In the first major part of this chapter (Part II), we turn to a consideration of each of these domains of non-moral normative value, presenting in each case a brief geography of the key conceptual issues and/or controversies engendered by each domain. Importantly, our aim in these sections will not be to settle definitively these controversies, but rather to show what issues are at stake in the respective disputes. Since our purpose in these sections is primarily analytical rather than polemical, it will suffice to raise these questions without answering them here. However, although these sections are primarily expository, they nevertheless serve an important function in the larger structure of this chapter, by providing important background in terms of which the chapter's subsequent discussion is developed. As we will see, many of the issues and questions that surface in the earlier sections of the chapter will recur again in the later sections. Specifically, the second half of the chapter seeks to show how the deafness debate illustrates the interaction of moral and non-moral normative issues in the identification of states of affairs as

'impairment' and 'disability.' Toward the end of the chapter, we will develop a tentative answer to a difficult epistemological question that plagues the "deafness debate." That tentative answer should provide some clues as to how we might go about answering some of the questions and difficulties raised in the earlier sections of the chapter; an extended development of those answers, however, would take us beyond the scope of this present work and so will be postponed for another occasion.

The next major portion of this chapter (Part III) addresses the second key question noted above—namely, the question of the role played by *moral* normative considerations both in understanding disability and in judgments regarding the appropriate social response to disability. Central to this discussion is a consideration of the question of the relationship between impairment and opportunity—specifically, *is impairment inherently opportunity-limiting?*—and an exploration of the implications that the answer to that question might have for the relationship between the disabled and the broader society.

Finally, in the last major portion of the chapter (Part IV), we build on the earlier sections to draw some general conclusions regarding the role of moral and non-moral normative values in identifications of states of affairs as "impairment" and "disability," as well as in judgments regarding appropriate social responses to disability. Using Rachel Cooper's (2007) article entitled "Can it be a Good Thing to be Deaf?" as a touchstone for further discussion, we consider deafness as an example of a condition that brings together all three domains of non-moral normative values—aesthetic, cultural, and epistemic—discussed here, as well as various moral normative considerations, and then go on to query whether and to what extent the "deafness debate" can be generalized to other forms of disability as well.

II. NON-MORAL NORMATIVE ISSUES

A. Impairment, Disability, and Aesthetic Values

Stated in the most general terms, the non-moral normative question under consideration in this portion of Chapter 5 is the non-moral normative question of whether disability is intrinsically/necessarily bad or only instrumentally/contingently so—or, to put the question in slightly different terms, is disability good/bad on balance vs. good/bad *simpliciter*? This is, of

course, a very large question, one that we cannot hope to answer definitively here. Instead, we focus our attention on one aspect of what is involved in *arriving* at an answer to that question.

Before proceeding further, however, it is worth pausing to note the significance of the larger question. As it turns out, the answer to this question has important implications, both within the disability community itself, as well as for broader questions of public and social policy; thus, any comprehensive analysis of the concept of disability must engage with this dispute at some point.

In particular, the answer to this question will have important implications for at least two domains. First, for disputes within various disability communities—for example, the contentious debate within the deaf community concerning the use (or foregoing) of cochlear implants to "correct" for deafness (see Papsin & Gordon, 2007, p. 2385). Should deaf persons receive cochlear implants? Why or why not? If being deaf is something bad—particularly if it is *intrinsically* bad—then correcting for deafness by means of cochlear implants would appear to be morally licit, even if not morally required.

Second, this has important implications for public and social policy as well. For example, if disability is *intrinsically* bad, then this may provide warrant for public policies that seek to eliminate or ameliorate disability—perhaps at great cost to society or to individuals. On the other hand, if disability is only *contingently* bad, then this may undermine the warrant for such policies, particularly those that rely (to one extent or another) on coercion to accomplish their aim (e.g., forced sterilization of the mentally retarded). Clearly, the role of non-moral values in determinations of disability will loom large in the answers to these various questions (see Cooper, 2007; Ralston & Ho, 2007).

We have noted on numerous occasions throughout this work that determinations and evaluative judgments about impairment and disability are made, in part, against the backdrop of various aesthetic considerations, including ideals of form and function, beauty, and so forth (Engelhardt, 2006). (As before, these determinations and judgments may vary, too, depending on the type, severity, and modality, etc., of the condition in question.). One key subset of these considerations has to do with the question of the relationship between certain aesthetic

experiences (listening to a symphony, watching a sunset, etc.) and/or the exercise of certain "standard" capacities or functions (seeing, walking, hearing, etc.) on the one hand, and the value, if any, that might inhere in the enjoyment of such experiences and/or exercise of those capacities or functions, on the other. To put the point more concisely, we can raise the following two questions: (a) are there intrinsically valuable aesthetic experiences? and (b) is the exercise of "standard" functions or capacities (seeing, hearing, walking, etc.) intrinsically valuable? If one answers either of these two questions in the affirmative, then we are immediately faced with two further questions: (c) does disability preclude the enjoyment/exercise of such (intrinsically valuable) experiences/capacities? and if so, (d) does that render disability itself intrinsically disvaluable?

As noted, we will not attempt in this present context to settle all these questions definitively. We will, however, provide an overview of the issues at stake in the debates over these questions, and identify the working assumption(s) upon which subsequent discussion in this work will proceed. To simplify our discussion for present purposes, we will focus our attention on the question of whether or not there are intrinsically valuable *experiences.* With that in mind, we can frame our overarching question as follows: *is disability intrinsically bad (i.e., disvaluable)?* The answer to that question will turn in part on our answers to the following sub-questions/issues:

(1) Are there intrinsically valuable experiences?

(2) If so, do certain impairments preclude the enjoyment of such experiences?

(3) If so, is this intrinsically bad? That is to say, does impairment involve a *specific* loss of intrinsic value?; and

(4) If so, does this then entail an *overall* loss of intrinsic value (in the life of the one thus impaired)?

Earlier in this work (see Ch. 4) we argued that disability is grounded, ontologically speaking, in an objectively real impairment. So, if our answer to question (4) is affirmative, then it would seem that we must answer our overarching question—*is disability intrinsically bad (i.e., disvaluable)?*—in the affirmative as well, for an overall loss of intrinsic value would appear to be a paradigm case of an intrinsically disvaluable condition. The key difficulty here, of course, lies in whether or not an

affirmative answer to question (3) *entails* or *necessitates* an affirmative answer to question (4). In light of these considerations, we can now focus our discussion further by inquiring specifically as to whether or not impairment precludes intrinsic value—and, if so, what implications (if any) follow from that fact.

1. Intrinsically valuable experiences?

As suggested above, these questions raise a number of related issues, including the goodness or badness (intrinsic or otherwise) of the various sensory modalities, "standard" modes of functioning, and the like. Is the possession of "standard" sensory capacities intrinsically good or bad? Does the possession or lack of such capacities effectively open or foreclose the possibility of the enjoyment of intrinsically valuable *experiences?* When it comes to the enjoyment of intrinsically valuable experiences, is "the more the better" the operative principle? Have past interventions or policies arbitrarily restricted the range of "meaningful opportunities" (or experiences, etc.) available presently to members of a non-dominant group, such as the disabled (Silvers, 1998)? If so, does this have any effect on our judgments concerning the intrinsic goodness or badness of a given sensory modality, sense experience, or "standard" mode of functioning? The fundamental questions, then, can be summed up as follows: are there intrinsically valuable *experiences*, which experiences necessarily require certain *modes of functioning,* such that a lack of ability to function in certain *modes* (i.e., an impairment) renders one *disabled*—and, if so, does this thereby render disability *intrinsically* bad?

Disagreement persists regarding the extent to which the possession and/or exercise of "standard sensory and motor functions" (such as seeing, hearing, and walking), and closely-associated actions, involves intrinsic or instrumental value. Moreover, even if the value in question *is* intrinsic (as opposed to merely instrumental), there is the further question whether that intrinsic value inheres in the actual *exercise* of a given sensory or motor function, or only in the "internal" *experience* associated with the exercise of such functions. If one opts for the latter disjunct, then the functions themselves would appear to be (only) instrumentally valuable, and the loss of value imposed by impairment would be a contingent loss. Here, thought experiments such as Nozick's (1974) "experience machine" loom large in the discussion. Does *experience* alone

matter, or does *achievement* (by means of certain actions) also matter (Wasserman, 2001, p. 232)?

A further, perhaps more fundamental, dispute concerns the following question: granting that certain standard sensory or motor functions and their closely-associated activities do have intrinsic value, how does the loss of such functions affect the impaired individual's overall well-being—if at all?[2] For example, given that standard sensory and motor functions can be a source of intrinsically-valuable aesthetic experiences (e.g., experiences involving beauty or complexity), does it follow that the *lack* of certain standard sensory or motor functions entails a significant loss of overall well-being? Conditions such as color blindness and tone deafness clearly exclude broad ranges of rich aesthetic experience, yet we would not typically conclude that tone-deaf or color-blind persons lead lives that are, *on balance*, significantly deprived of overall well-being, despite their lack of certain intrinsically valuable experiences. The upshot of this is, as Wasserman puts it, that "we cannot infer from the fact that there is great intrinsic value in a basic action that those who cannot perform that action have lives with significantly less value" (Wasserman, 2001, p. 233); consequently, "once we distinguish the absence from the loss of valuable sensory and motor experiences, there is no reason to believe that the absence of intrinsically good experiences is intrinsically bad" (Wasserman, 2001, p. 233, citing Silvers et al., 1998). For one thing, the absence of one sensory function may actually serve to enhance one's ability to concentrate on, and therefore appreciate, the remaining functions. Moreover, "we do not make the assumption that unimpaired people who can, but do not, have particular sensory or motor experiences necessarily lead impoverished lives" (Wasserman, 2001, p. 233, citing Silvers et al., 1998).[3]

Returning now to the four sub-questions questions/statements identified above, with which we began this section, the upshot of these considerations would appear to be fairly

---

[2] For recent discussion of this and related issues, see Cooper (2007).

[3] These are, of course, controversial claims—and Wasserman is quick to acknowledge that such arguments may take an "overly narrow view" of the intrinsic value of certain sensory and motor functions (Wasserman, 2001, p. 232). In particular, it may be, as Magee and Milligan (1995) suggest, that the possession of sensory functions related to seeing and touch are crucial to connecting persons with the physical and social world (Wasserman, 2001, p. 233, citing Magee and Milligan, 1995, pp. 105-106). Even so, Wasserman insists, there is room for debate as to whether *both* of these—i.e., seeing *and* touch—are required in order to prevent such isolation, nor, he says, is it immediately obvious that the other senses are comparably important (Wasserman, 2001, p. 233).

The considerations raised here paragraph bring to mind the distinction, discussed in Chapter 4, between being disadvantaged *simpliciter* and being disadvantaged "on balance."

straightforward: any alleged entailment from an affirmative answer to question (3) to an affirmative answer to question (4) is, at the very least, not *obviously* a necessary one. Specifically, the claim that the loss of intrinsically valuable experiences/capacities entails a significant *overall* loss of intrinsic value will require substantial supporting evidence at minimum—and, indeed, may be ultimately unsupportable. For this reason, we will for our purposes treat as presumptively suspect the claim that disability *necessarily* involves an *overall* loss of intrinsic value, while nevertheless affirming the possibility that, at least in many instances, it can involve the loss of certain *specific* intrinsically valuable experiences or capacities.

B. Impairment, Disability, and Cultural Values

1. Is disability a "form of culture"...?

Along similar lines as the "neutral variation" approach (see Chapter 4), some disability advocates have argued that disability is best understood as a form of "culture." Most notably, some advocates from the Deaf community have argued that deafness amounts to a separate, self-sustaining culture—"Deaf culture"—and that any discrimination against deaf persons constitutes unjust discrimination on the basis of (mere) cultural differences.

This raises a host of thorny questions—among them, whether "disability" is indeed best understood in cultural terms, whether we can coherently speak of a "disability culture" generally, or of specific impairment-related disability cultures, e.g. "Deaf culture." Further, if one can coherently speak of "disability culture," can one also mount successfully an argument against discrimination on the basis of one's "disability culture," along similar lines as those arguments advanced by other, recognized cultural "minorities" (e.g., ethnic, racial, and religious groups) [cf. Berbrier, 2002; Gleason, 1991]? Is disability ever a morally relevant basis for discrimination? If discrimination is ever justified, does that justification require that disability have a biological substrate (i.e., basis)? If the *only* way in which persons with disabilities are "different" is in having a different "culture," is discrimination against them (on that basis) *ever* appropriate?

In sum, if disability is to be understood in terms of "culture," careful conceptual work will be required in order to delineate adequately the bounds of what can properly be considered "disability," as well as to parse out with precision the implications of such delineation. We also

need to have a better understanding of what is meant by "culture," and how people think about culture, at both the individual and group levels. In exploring these issues, the sociological literature on "culture" provides us with helpful theoretical and conceptual resources for understanding the claims being made by advocates for "disability culture." For that reason, in the following discussion draws upon some of the relevant sociological literature, with a particular view toward gaining a better understanding of (a) what *sort* of claim the claim to "disability culture" amounts to, and (b) what the *implications* of such a claim might be. Since claims to a distinct "culture" have been most prominent in the Deaf community, we will again use the "Deaf Culture Movement" as a paradigm example of these sorts of claims. In the next section, we review some research into the relation between "culture and cognition" (DiMaggio, 1997) in order to glean some key theoretical insight, the importance and relevance of which will become apparent in later sections of this chapter.

a. What is culture? Themes from the sociological literature

In an article entitled "Culture and Cognition," DiMaggio (1997) focuses his analytical attention on how people *use* culture. In this context, he draws on research in cognitive psychology to show that "culture" involves an interaction between "shared cognitive structures" and "supra-individual" phenomena such as "material culture, media messages, or conversation" (DiMaggio, 1997, p. 264). Specifically, on the account developed by DiMaggio, supra-individual phenomena *activate* shared cognitive structures to produce "culture" (DiMaggio, 1997, p. 264).

DiMaggio's aim in this paper is to show how research in cognitive psychology can inform sociological research into culture, and vice versa. He begins by noting a "convergence" in the two fields toward "more complex" views of cognition and culture, respectively. Sociologists, he observes, have increasingly come to reject a notion of culture as a "seamless web," as "unitary and internally coherent across groups and situations." Instead of viewing culture as a "latent variable—a tight network of a few abstract central themes and their more concrete entailments, all instantiated to various degrees in a range of symbols, rituals, and practices" (DiMaggio, 1997, p. 264, 266)—sociologists have come to adopt a view of culture as "fragmented across groups and inconsistent across its manifestations" (DiMaggio, 1997, p. 266, citing Martin, 1992). On this

view, "culture" consists of "complex rule-like structures that constitute resources that can be put to strategic use (DiMaggio, 1997, p. 264, citing Bourdieu, 1990, Sewell, 1992, and Swidler, 1986). Here, "culture" is more properly thought of as "a grab-bag of odds and ends: a pastiche of mediated representations, a repertoire of techniques, or a toolkit of strategies"—a "toolkit" which, DiMaggio reports, has been shown in recent research by cognitive psychologists to be "very large indeed" (DiMaggio, 1997, p. 266). For example, DiMaggio cites research into "how people attribute accuracy or plausibility to statements of fact and opinion" which, he says, has shown that "[t]he acceptance of an idea is a part of the automatic comprehension of that idea, and the rejection of the idea occurs subsequent to and more effortfully than its acceptance" (Gilbert, 1991, quoted in DiMaggio, 1997, p. 266). "In other words," DiMaggio explains, "our heads are full of images, opinions, and information, untagged as to truth value, to which we are inclined to attribute accuracy and plausibility" (DiMaggio, 1997, p. 266). As we will see later, one of the key rhetorical strategies of disability rights activists is to challenge various received "images, opinions, and information" that people tend to take for granted regarding persons with disabilities (cf. the discussion, later in this chapter, of Amundson's critique of the "Standard View" of disability).

Cognitive psychologists, meanwhile, have also moved toward "more complex views of cognition" (DiMaggio, 1997, p. 265). In particular, researchers in this field have increasingly come to recognize the role that "shared cognitive structures" can enter into individual cognition, so that culture is in an important way "supra-individual" (DiMaggio, 1997, p. 266).

The view of culture as "fragmented," DiMaggio argues, has a number of important implications for sociological research into culture. First, he says,

> it refutes the notion that people acquire a culture by imbibing it (and no other) through socialization. Instead, it directs the search for sources of stability and consistency in our beliefs and representations, first, to schematic organization, which makes some ideas or images more accessible than others; and, second, to cues embedded in the physical and social environment (DiMaggio, 1997, p. 266).

In other words, "culture" is arrived at (or developed) through an *active* process of "schematic organization," a process that renders certain ideas or images more *accessible* or *plausible* than

others. Consistency and stability in one's cognitive structures is arrived at through this active process of schematic organization in interaction with environmental (physical, social) and other cues.

Another important implication of this research, DiMaggio argues, is that it "explains the capacity of individuals to participate in multiple cultural traditions, even when those traditions contain inconsistent elements" (DiMaggio, 1997, p. 268). For example, a deaf lesbian may see herself as belonging to at least three distinct "cultural tradition"—namely, the deaf culture, the lesbian culture, and female culture; similarly, a black male with a physical disability may consider himself to be part of both a "racial" and a "disability" culture.

More generally, the upshot of this research into cognitive psychology is, on DiMaggio's account, that schematic organization "imposes order upon stored knowledge and memory." Thus, DiMaggio contends,

> recent cognitive research strongly reinforces the "toolkit" as opposed to the "latent-variable" view of culture and, at the very least, places the burden of proof on those who depict culture as strongly constraining behavior or who would argue that people experience culture as highly integrated, that cultural meanings are strongly thematized, that culture is binding, and that cultural information acquired through experience is more powerful than that acquired through other means (DiMaggio, 1997, p. 268).

The important implication of this contention, in turn, is that "culture" has *both* a constraining and enabling function. On the one hand, "culture, embedded in language and everyday practices, constrains people's capacity to imagine alternatives to existing arrangements" (DiMaggio, 1997, p. 268). In this regard, disability rights activists will often argue that the limitations experienced by persons with disabilities is, in many cases, a function of a lack of attention to the possible alternative modes in which standard functions might be pursued (cf. the discussion of Anita Silver's proposal of "historical counterfactualizing," later in this chapter). On the other hand, "we [also] know that people act as if they use cultural elements strategically to pursue valued ends" (DiMaggio, 1997, p. 268, citing Bourdieu, 1990)—that is, people are (under certain

circumstances) able to *transcend* the influence of culture. Culture, in other words, is highly *influential* but not (strongly) *determining*.

The "constraining" and "enabling" functions of culture operate by means of different "modes of cognition" (DiMaggio, 1997, p. 268)—"automatic cognition" and "deliberative cognition," respectively. On the one hand, "...routine, everyday cognition relies heavily and uncritically upon culturally available schemata—knowledge structures that represent objects or events and provide default assumptions about their characteristics, relationships, and entailments under conditions of incomplete information" (DiMaggio, 1997, p. 269).[4] Schemata, DiMaggio says, simultaneously *represent* knowledge in certain kinds of ways and serve as "information-processing mechanisms"; as such, they function as cognition-simplifying mechanisms (DiMaggio, 1997, p. 269). They can include, among other types, what has been termed "self schemata": "culturally variable representations of the self that provide stability both to individual behavior across time and to social interactions within the group" (DiMaggio, 1997, p. 269, citing Milburn, 1987, Markus & Kitayama, 1994, and Markus et al., 1997). In short, "[i]n schematic cognition we find the mechanisms by which culture shapes and biases thought" (DiMaggio, 1997, p. 269).

There are, DiMaggio reports, at least four central ways in which schematic cognition "shapes and biases thought." First, "*[p]eople are more likely to perceive information that is germane to existing schemata"* (DiMaggio, 1997, p. 270, italics in original). This has been borne out repeatedly in the literature on the sociology of medicine. Ludwig Fleck (1979), for example, in his *Genesis and Development of a Scientific Fact,* has demonstrated "the ways in which archaic physical models constrained medical scientists' interpretation of new evidence about syphilis" (DiMaggio, 1997, p. 270). That is, given their prior commitment to certain schematic structures (i.e., "archaic physical models"), scientists initially found it difficult to interpret "new evidence about syphilis." Second, "*[p]eople recall schematically embedded information more quickly*" (DiMaggio, 1997, p, 270, italics in original). Third, "*[p]eople recall schematically embedded information more accurately*" (DiMaggio, 1997, p, 270, italics in original). And, fourth, "*[p]eople*

[4] As we will see later in this chapter, this is the crux of Amundson's (2005) critique of what he terms the "Standard View" of disability—namely, that it relies upon unfounded but uncritically accepted assumptions about the lives of persons with disabilities.

may falsely recall schematically embedded events that did not occur" (DiMaggio, 1997, p, 271, italics in original).

Culture, embedded in such "schemata," can thus constrain cognition in important ways. Nevertheless, DiMaggio argues, "[r]esearch on social cognition... does not support theories that depict culture as overwhelmingly constraining. Instead, consistent with contemporary sociological theorizing, work in psychology provides microfoundational evidence for the efficacy of agency"—that is, for the existence of "deliberative" as well as "automatic" cognition (DiMaggio, 1997, p. 271). Indeed, DiMaggio says, "[w]hen sufficiently motivated, people can override programmed modes of thought to think critically and reflexively" (DiMaggio, 1997, p. 271). This sort of "deliberative" cognition is triggered, in particular, by three main factors: (1) attention, (2) motivation, and (3) schema failure. First, "[p]sychological research suggests that people shift into deliberative modes of thought relatively easily when their attention is attracted to a problem" (DiMaggio, 1997, p. 271). Second, "[p]eople may also shift from automatic to deliberative cognition when they are strongly motivated to do so by dissatisfaction with the status quo or by the moral salience of a particular issue" (DiMaggio, 1997, p. 271). And third, "people shift to more deliberative modes of processing when existing schemata fail to account adequately for new stimuli" (DiMaggio, 1997, p. 272).

The research on these two types of cognitive processing underscores the notion that "both institution and agency are central to social life"—that "culture" is both individual *and* "supra-individual" (DiMaggio, 1997, p. 272). In other words, as DiMaggio puts it, culture exists at both the collective level *and* the individual level, "in people's heads" (DiMaggio, 1997, p. 272). The "supra-individual" aspect of culture is manifested, according to DiMaggio, in four key phenomena, which he classes under the following headings: "pluralistic ignorance," "intergroup contrast and polarization," "schemata as culture," and "coherent cultures as external to persons." First, the term "pluralistic ignorance"—which is drawn from the research of Robert K. Merton (see Merton, 1957)—refers to

> the idea that people act with reference to shared representations of collective opinion that are empirically inaccurate. Such research directs us to distinguish between two senses in

> which culture is supra-individual: as an aggregate of individuals' beliefs or representations, or as shared representations of individuals' beliefs. Substantial evidence indicates that the latter deviates substantially from the former with significant behavioral consequences and that this process represents a basis for the relative autonomy of social norms (DiMaggio, 1998, pp. 272-273, citing Miller & Prentice, 1996 and Noelle-Neumann, 1993).

Second, "[t]he existence of group-level cultures (shared understanding partly independent of individual beliefs) is also suggested by the tendency of groups to adopt public positions more extreme than the preferences of their members, especially when acting with reference to a contrasting group"—what DiMaggio refers to as "intergroup contrast and polarization" (DiMaggio, 1997, p. 273). Third, "[m]any schemata,... and the schemata of greatest interest to sociologists of culture, enact widely held scripts that appear independent of individual experience" (DiMaggio, 1997, p. 273).[5] Finally,

> relatively coherent cultural forms exist independently of persons in the broader environment. Indeed, one of the more notable characteristics of modern societies is the existence of a cultural division of labor in which intellectual producers intentionally create and diffuse myths, images, and idea systems (DiMaggio, 1997, p. 273, citing Douglas, 1986, Farr & Moscovici, 1984, and Swidler, 1997).

In sum, DiMaggio argues, the research reviewed in his paper support the notion that culture is the product of the interaction of three key elements, or "forms":

> First, we have information, distributed across persons (Carley 1991). Such distribution is patterned, but not highly differentiating, due to the indiscriminant manner in which bits of culture are accumulated and stored in memory (Gilbert 1991). Second, we have mental structures, especially schematic representations of complex social phenomena, which shape the way we attend to, interpret, remember, and respond emotionally to the information we encounter and possess. Such schemata are more clearly socially patterned

[5] This point is relevant to the debate, discussed elsewhere in this work, over whether or not there is such a thing as a "disability role." Further development of this point here would, however, take us beyond the scope of the present discussion.

than are memory traces. Finally, we have culture as symbol systems external to the person, including the content of talk, elements of the constructed environment, media messages, and meanings embedded in observable activity patterns (DiMaggio, 1997, p. 273).[6]

In other words, "[c]ulture inheres not in the information, nor in the schemata, nor in the symbolic universe, but in the interactions among them" (DiMaggio, 1997, p. 273). Available "schemata" are *activated* by certain environmental "cues" or "frames; once activated, schemata then *structure* information, affecting how information is perceived, interpreted, and retained (DiMaggio, 1997, p. 274). As DiMaggio explains the point,

> ...selection [of schemata] is guided by cultural cues available in the environment. Although a few schemata may be chronically available, more often they are primed or activated by an external stimulus or frame.... Framing effects in social surveys—e.g. the finding that whites are more likely to accept negative stereotypes of African-Americans if the question is preceded by a neutral reference to affirmative action... —are familiar examples. But schemata can also be activated through conversation, media use, or observation of the physical environment (DiMaggio, 1997, p. 274, citing Sedikides & Skowronski, 1991, Barsalou, 1992, Gamson, 1992, pp. 6-8, Schudson, 1989, and Sniderman & Piazza, 1993, pp. 102-104).

For our present purposes, perhaps the most important upshot of the foregoing discussion is that in light of recent sociological and cognitive psychological research, the Disability Rights (DR) movement can be seen as attempting to change the *frames* in terms of which *schemata* about disability and the disabled are activated—which affects, in turn, how information about the disabled is processed, interpreted, and responded to.

b. Bases for claims of a disability culture

According to Peters (2006, p. 412), "[a] universal definition of *culture* is the sum of behaviors, beliefs, ways of living, and material artifacts characteristic of a particular group or society." The term thus implies a "shared way of life" (Barnes & Mercer 2001, pp. 515-516) and

[6] The process described here is reminiscent of Kant's constructivist epistemology. Here again, however, further development of this observation would take us too far afield for present purposes.

encompasses the "pursuits of the whole population" (Barnes & Mercer, 2003, p. 89) or of the particular group in question.

The key question in this context is whether any specific group shares a "way of life" (cf. Bahan & Parish, p. 349) to a sufficient degree that it can plausibly be understood or referred to as being or having a distinct "culture." Specifically, one can query whether there is a "distinctive disabled people's culture" (Barnes & Mercer, 2003, p. 101). Proponents of the notion of a "disability culture" typically base their claims to a distinct culture on (1) historical, (2) social/political, and/or (3) personal/aesthetic grounds.[7] Common themes underlying such arguments include the notions that disabled persons share a "common identity,"[8] an affirmation of "disabled identity/consciousness," and a rejection of impairment as a legitimate "symbol of shame/pity" (Barnes & Mercer, 2001, p. 522).

Barnes and Mercer helpfully delineate and summarize some of the key assumptions embedded in arguments advanced by proponents of the notion of a distinct "disability culture." According to Barnes and Mercer,

> [d]isability culture presumes a sense of common identity and interests that unite disabled people and separate them from their non-disabled counterparts. The exact bases for social group cohesion and consciousness will vary, as will the level and form of any engagement in cultural activities. This division between 'insiders' and 'outsiders' is

---

[7] "Particular definitions of culture—such as *disability culture*—take many different forms and are context bound (dependent on the cultural and geographic context in which they are formed). Three common ways of thinking about disability culture are historical, social/political, and personal/aesthetic. Historical definitions of disability culture focus on art, poetry, language, and social community developed by disabled people. Social/political definitions of disability culture focus on a minority group distinction with common values of social and economic justice, radical democracy, and self-empowerment. Personal/aesthetic notions of disability culture emphasize a way of living and positive identification with being disabled" (Peters, 2006, p. 412).

[8] DiMaggio (1997, discussed above) concludes his paper with a consideration of several possible sociological applications of the research in cognitive psychology he has detailed here. One important area of potential application is in developing more robust theories of collective and individual identity. In this regard, DiMaggio suggests, the research he has examined in this paper shows that, on the one hand, "[a]t the supra-individual level, collective identity is a shared representation of a collectivity"—that is, collective groups themselves have an "identity" that is more than just an "aggregate" of the identities of that group's individual identities (and, indeed, may differ from those individual identities) [DiMaggio, 1997, p. 274-275). On the other hand, *collective* identities can actually "enter into" the identity of individuals. As DiMaggio puts it,

> [m]uch research on collective identity is actually about the more complex issue of the ways in which social identities enter into the constitution of individual selves. Social identity theory views individual identities as comprising prioritized identity-sets based on particularistic and role-based group affiliations.... Self-categorization theories also portray collective identities as invoked by conditions that make particular identities especially salient.... In this view, individual identities reflect elaborated group-identity schemata in proportion to strength and recency of activation. Viewing identities as context-dependent in this way is consistent with observations of the volatility with which identities may gain and lose salience during periods of intergroup conflict (DiMaggio, 1997, p. 275, citing Stryker, 1986 and Tajfel & Turner, 1986).

Here again, we see the salience of these research findings to the broader dispute over the existence and nature of a "disability role."

> developed and maintained by specific cultural styles, customs, and social interaction, such as in segregated, residential schooling, or by a distinctive set of experiences. There is a further presumption that a disability culture rejects the notion of impairment difference as a symbol of shame, and stresses instead solidarity and a positive identification.[9] At the same time, a general disability culture may be contrasted with subcultures located around specific impairment groups. Furthermore, because most disabled people acquired their impairment in later life, their embrace of disability culture is inhibited by their previous immersion in a non-disabled environment (Barnes & Mercer, 2003, p. 102).

Of course, as Barnes and Mercer point out, "[w]hatever one's conclusions regarding this debate, further questions remain[10] about the value or possibility of a separate cultural identity" (2003, p. 102). The following subsection raises some of these questions and implications.

2. Implications and critical questions

The foregoing gives rise to a number of implications and important critical questions.

First, what is the domain of "disability culture"? Is there a singular disability culture/community, or are there multiple disability cultures/identities? Or, to put the question differently, if there is a "general" disability community/culture, are there also disability "subcultures" within that general disability culture? Moreover, what distinguishes a disability community/culture from, say, a linguistic or ethnic community/culture? In particular, is the "Deaf community" a disability community, a linguistic community—or both (cf. Berbrier, 2002)? If there are multiple "disability communities," what distinguishes them from one another?

The difficulties associated with conceptualizing disability in terms of "culture" can be seen especially clearly when one considers the Deaf community and its claims to being a distinct "culture." Along these lines, Deaf culturists frequently insist that deafness is not a disability.

---

[9] The "difference" constituting "disability culture" is, on this view, intentionally affirmed; as Peters puts it, "[t]oday, celebrating difference has become the mantra and visible manifestation of the disability culture in all regions of the world" (2006, p. 415). Indeed, on one such account, "[d]isability culture is built on the premiss that there is a moral and political obligation to celebrate difference" (Barnes & Mercer, 2003, p. 106).

[10] In this regard, Barnes and Mercer cite disability advocate Vic Finkelstein's articulation of two such questions: Firstly, there is a great deal of uncertainty amongst disabled people whether we do want 'our own culture'. After all, we all have had the experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society do we want to go off at a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity for us to develop a cultured life" (Finkelstein, quoted in Campbell and Oliver 1996: 111, quoted in turn by Barnes & Mercer, 2003, p. 102).

However, there is a tension here, as those who claim that deafness is not a disability frequently also support policies of accommodation as prescribed by legislative actions like the Americans with Disabilities Act (1990). Thus, they simultaneously claim that deafness is not a disability that needs to be "fixed" (cured), while also affirming that it is a "disabling condition" for which deaf persons ought to be compensated and/or accommodated. Indeed, Deaf culturists frequently reject attempts to "cure" deafness, while simultaneously demanding often-costly accommodations for deaf persons. Tucker (1997) refers to these commitments as "contrasting precepts" that yield "conflicting results."

The notion of "Deaf culture" raises a number of additional questions, both theoretical and practical in nature, among which are the following: If deafness is a *culture/cultural minority,* then (a) is it a disability? (b) is it a uniquely *disadvantaged* culture? (c) is it something that should be compensated for? Turning the question around, if deafness is a *disability,* then (a) is it (also) a "culture"? (b) is it a condition that should be compensated for? If deafness *is* a disability, then we might raise further questions turning on the distinction between negative and positive rights: (a) do deaf persons have a negative right to *refuse* treatment/correction? Conversely, do they have a positive right to *demand* compensation/provision of services? (Tucker, 1997). If corrective technology for deafness is available, does this create a positive *obligation* to avail oneself of that technology? If corrective technology is available, does the refusal to accept such therapy affect one's positive rights to subsequent compensation or provision of services? If so, how? Finally, with respect to the costs of accommodation related to deafness (e.g., schools, special colleges, relay services, auxiliary aids and accommodations, etc.), who should pay for such costs? If "treatment"/"cure" (when available) is refused, who bears the subsequent costs? Are there legitimate limits on "rights" to treatment, cure, accommodation, and the like? (Tucker, 1997).

In sum, what are the relevant moral/ethical obligations—of society to deaf persons? Of deaf persons to society? In response to these questions, Tucker (1997) argues that the moral/ethical obligations are a two-way street: while society does have obligations to deaf persons, it is also the case that deaf persons have obligations to society. In particular, Tucker argues that if a deaf person refuses "corrective" technology (when and if such technology

becomes available) then that individual should bear the costs of accommodating her uncorrected deafness (Tucker, 1997).

One can see in these various questions, and the discussion surrounding them, the influence of postmodernism and poststructuralism generally, and of Marx, Foucault, and the deconstructionist movement in particular (Barnes & Mercer, 2001, pp. 89-90). The challenge of postmodernism forces us to ask the question: can one even speak coherently of *a* "disability culture"—or only of multiple disability cultures/identities (cf. Davis, 2001)?

The notion of "disability as culture" owes much as well to the influence of identity politics, which in turn leads us to inquire as to the objectivity (or value-neutrality) of identity politics, as well as the implications of embracing an identity politics approach. As Davis (2001) and Reinders (2008) among others have argued, identity politics inevitably poses difficulties for the disability community, particularly for certain subgroups within that community. For Reinders, the central problem with identity politics is that it both assumes and reinforces a "hierarchy of disability," in which an insistence on the right of persons with disability to "tell their own story," coupled with an emphasis on the importance of "selfhood and purposive agency" as being central to "what makes our lives human in the first place," has the effect of relegating persons with intellectual disabilities (especially those with profound intellectual disabilities) to the lowest ranks of the hierarchy, because their capacities for developing "selfhood" are comparatively limited (Reinders, 2008, pp. 24-27). As a consequence, the notion of "disability culture" may turn out to be insufficiently broad to include those with intellectual disabilities (Reinders, 2008; cf. Davis, 2001). For Barnes and Mercer, the notion of disability culture represents a "politicization of disabled people" (Barnes & Mercer 2001, pp. 531-532)—a "new cultural politics of difference" that creates a unique "dilemma" for the disabled community (Barnes & Mercer, 2001, pp. 531-532). This "dilemma," these authors contend, arises from the fact that, on the one hand, unified political action requires organization around some similarity in virtue of which the members of a group—in this case, "disabled people"—can be classed together. On the other hand, it is precisely this sort of "essence" that

identity politics seeks to deconstruct.[11] Moreover, as Barnes and Mercer point out, disabled persons also live as members of different classes, age groups, races, and genders. The question, then, becomes one of which identity(ies) they will embrace and advocate on behalf of, and how to proceed when the agendas of different "identity groups" conflict with one another. In short, "the dilemma is that disabled people, like other oppressed groups, have to constantly negotiate several kinds of difference, such as gender, race, class, and age, in their lives" (Barnes & Mercer, 2001, p. 532).[12] Consequently, "the impact of disability consciousness and culture has not been evenly felt across the disabled population" (Barnes & Mercer, 2001, p. 532).

A second, related set of considerations clusters around the question, what constitutes the unity of the class termed 'disability culture'—or, for that matter, the more general class denoted by the term 'disabled'/'disability'? Is "difference" the unifying characteristic? Type of impairment? Essence (i.e., some set of essential properties)?

How one answers these first two sets of questions will affect, in turn, how one answers a third set of questions clustering around the *political implications* of adopting the notion of "disability culture." For example, given the internal diversity evident within the disability community, is there a sufficient basis for "unified political action" on behalf of that community? What are the *political* implications of conceptualizing disability as "culture"? In other words, what is the relationship between "unity" and "difference"? Does an affirmation of "difference" undermine attempts to achieve unity? Peters suggests that it may very well do this, and refers to this as the "paradox" of disability culture. (Peters, 2006, p. 418). As we will see in Chapter 6, there are political implications to seeking recognition as a "minority" group, as many disability advocates seek to do. Indeed, "minority" status has become an increasingly desirable designation precisely *because* of potentially significant material and nonmaterial benefits that such "categorical status" can yield, politically and otherwise (Berbrier, 2002; Gleason, 1991).

C. Impairment, Disability, and Epistemic Values

---

[11] Gamson (1995) refers this as "the dilemma of identity movements," which, as Berbrier recounts it, amounts to the fact that "while claimants for identity movements assert essential, fixed, and natural identities, it is these very kinds of 'fixed identity categories [that] are both the basis for oppression and ... for political power'" (Berbrier, 2002, p. 582, quoting Gamson, 1995, p. 391).

[12] Recall the observation made earlier in this chapter that people are capable of participating "in multiple cultural traditions, even when those traditions contain inconsistent elements" (DiMaggio, 1997, p. 268).

A third domain of non-moral normative values that enter into determinations of impairment and disability is that of epistemic values. For example, questions of epistemic standing and privilege are strikingly salient in judgments regarding "quality of life." Other non-moral normative values (e.g., aesthetic values) are also implicated in interesting ways in such judgments, so a consideration of the role of non-moral normative values in quality-of-life judgments is especially pertinent to our project in this chapter. We therefore proceed by, first, laying out some of the theoretical and conceptual issues involved in "quality of life" judgments generally, and then moving on to consider issues related to epistemic standing and privilege, specifically in the context of judgments regarding the quality of disabled persons' lives.[13]

---

[13] Since the 1970s biomedical ethics has increasingly been concerned with "quality of life" as a key consideration in decisions related to health care (Wasserman, Bickenbach, and Wachbroit, 2005). Perhaps nowhere is the effect of this emphasis more evident than in the increased use in recent decades of prenatal genetic testing and associated practices such as selective termination on the basis of disability.

These developments in prenatal genetic testing and knowledge raise crucial questions regarding the meaning and significance of "quality of life." In the health care context, numerous attempts have been made to devise measures of the relative impact on "quality of life" (or QOL) of various health care interventions. For such purposes, the term "health-related quality of life" (or HRQL) has been coined. The problem, however, is that any attempt to measure or assess HRQL immediately runs into a conceptual difficulty—namely, "what outcomes (or types of outcomes) are connected closely enough with health to be taken account of in assessing the impact of health interventions on quality of life?" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 5). Put differently, the question here is: what is the theoretical link, or bridge, between "quality of life" as a general concept, and "health-related quality of life" as a specific instance of that broader concept? Narrowing the focus from "quality of life" to "health-related quality of life" is a practical necessity: since "virtually all areas of activity are affected by health," any attempt to assess the impact of a particular health intervention on quality of life will have to limit itself to consideration of "areas most directly or substantially limited by health" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 5). But of course, without prior agreement as to what will count as "health-related," the term "health-related quality of life" effectively "does more to label than to resolve" the problem at hand (Wasserman, Bickenbach, & Wachbroit, 2005, p. 5).

As Wasserman et al. point out, this difficulty—namely, the fact that there is little agreement concerning what falls within the scope of "health"—constitutes a "serious practical problem" (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 5-6). This practical problem stems in part from the fact that

[t]he notion of HRQL depends, both historically and conceptually, on the common observation that there is an uncertain relationship between diagnostic categories – the signs and symptoms that doctors use to identify disease, injury, and other conditions of ill health – and the full range of outcomes that, arguably, should be taken into account in assessing the success of a health intervention (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 5-6).

This practical difficulty also arises in part because "a wide variety of economic, social, and psychological factors mediate the impact of health conditions on the activities and states of mind that people value, and because those activities and states of mind vary in how closely they appear to be related to health" (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 5-6).

Moreover, aside from the difficulty of specifying what counts as "health-related" for purposes of assessing "health-related quality of life," there is an even more basic, fundamental problem—namely, the fact that the health professions "lack a theory of quality of life itself" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 6)—or, at least, they lack a single, agreed-upon theory of that notion.

In the context of disability, the focus on "health-related quality of life" is somewhat of a "double-edged sword" for persons with disabilities. On the one hand, as Wasserman et al. put it, "[i]t might appear that people with disabilities would welcome the growing interest of health professionals and policy makers in quality of life" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 10). On the other hand, "the increased attention of health professionals to a broader range of causal factors and outcomes may also have some troubling implications for people with disabilities" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 10). There are two primary worries here. The first worry has to do with changing understandings of the scope of the terms "health-related" and "health problem":

> ...as health professionals and policy makers have broadened the range of outcomes they regard as health-related, they have taken a correspondingly broader view of what counts as a health problem.... This expansive view of health problems appears to contradict, and to undermine, the effort of two generations of disability activists to present such difficulties as problems of environmental fit and social justice.... (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 10-11).

1. Quality of Life and Epistemic Standing: Who has epistemic standing to render judgments regarding quality of life?

In response to the claim that disabilities amount to disadvantages toward which preventative efforts (especially medical ones) ought to be directed, disability advocates have often advanced the argument that there is no good reason to think that their lives are, on balance, any worse by virtue of their disability than are the lives of those without disabilities. Prominent bioethicist Dan Brock (2005) acknowledges the initial plausibility of such claims. Numerous studies, for example, have shown that disabled persons typically rate their "quality of life" higher

---

The second worry centers around the fact that "those who assess HRQL tend to treat one of the core phenomena of disability – adaptation – as an artifact and a distortion" (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 10-11). The term 'adaptation' refers to the tendency among people who have experienced diminishment of functioning due to accident or disease to "report, despite initial disruption and feelings of loss, increasing satisfaction and proficiency with the passage of time, whether or not they receive a particular health intervention" (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 10-11). This poses a difficulty for attempts to gauge the effect on quality of life of different interventions; in particular, "[f]or those trying to gauge the broader success of an intervention, this background improvement presents a complication and possibly a confounding factor" (Wasserman, Bickenbach, & Wachbroit, 2005, pp. 10-11). Moreover,

> for those who attempt to develop accounts of quality of life or well-being based on objective functioning, such changes are often taken to reveal the inadequacy of more subjective measures, such as personal satisfaction, as an index of life quality or well-being.... Tiny Tim's euphoria, to use the classic example, is not taken as evidence of his doing well despite his impaired mobility, but as proof that his feelings have but a tenuous relationship to his quality of life. While disability advocates recognize the possibilities for self-deception and false consciousness, they would argue that Tiny Tim's euphoria should, at least at the outset, be taken at face value – that it should be regarded either as partially constitutive of a high quality of life, on a subjective account [of] quality of life, or as evidence of a high quality of life, on a suitably refined objective account (Wasserman, Bickenbach, & Wachbroit, 2005, p. 11).

These two conceptual worries raise, for the disability community, two chief areas of concrete concern—namely, "expressive" and "practical" concerns, respectively. First,

[t]he main expressive concern is that the treatment of the personal and social challenges of people with disabilities as health problems, and of their satisfaction in the face of those problems as suspect, supports a false, demeaning impression of the impact of impairment (Wasserman, Bickenbach, & Wachbroit, 2005, p. 11).

This "expressive" concern leads, in turn, to a "practical" concern that this "misleading impression" will "jeopardize the hard-won gains of disability advocates in framing the challenges of impairments as problems of environmental design and social justice rather than, or as well as, problems of health" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12). Instead, on this view, "in the health care and health policy fields,... treating disability as a health problem more often leads to its medicalization" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12).

In this regard, disability advocates point to two policies that they see as being "particularly threatening" to persons with disabilities—namely, "the assignment of lower priority to the preservation of disabled lives in allocating scarce resources, and the development of health practices designed to reduce or eliminate the creation of people with such impairments" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12). Of course, as Wasserman et al., acknowledge, neither of these policies is strictly entailed by "[t]he belief that people with disabilities must lead lives of lower, or at least substantially lower, quality because of their impairments" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12)—the view that is the primary target of the "expressivist" concern noted above. Indeed, "the second policy does not entail the first, and many who support the second... strongly oppose the first" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12). Still, they say, there is clearly "some association between that view and those policies, especially in light of the historical role of quality-of-life considerations as a basis for ending, or not extending, severely impaired lives" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 12).

These concerns lend impetus to the move toward "reconceptualizing" disability "as an interaction rather than a condition or property of an individual," what Wasserman et al. describe as "perhaps the leading theoretical achievement of the disability rights movement" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 13). On this "interactive" model,

> disability is a product of, or an interaction between, the biological dysfunctions of the individual's body or mind (usually called impairments) and the social and physical context or environment in which the person lives.... To be disabled is, roughly, to have limitations on the activities and roles one can perform that result in part, but only in part, from biological dysfunction. Those limitations also depend on the environment, on physical or social obstacles that limit, prevent, or fail to promote performance. Disability, therefore, is not a feature of an individual's body or mind, but a complex interaction of biological features of the individual and features of the physical and social environment (Wasserman, Bickenbach, & Wachbroit, 2005, p. 13).

than do nondisabled people, including their family members, physicians, and other close associates. Brock offers two hypotheses as to why this might be the case:

> First, societal prejudices and stereotypes about disabled persons and their lives remain powerful and strongly influence common beliefs – many of which are false beliefs – about disabled persons and their lives.[14] Second, disabled persons often succeed in reducing or even eliminating the negative impact of disability on their lives (Brock, 2005, p. 73).[15]

In light of these considerations, Brock concludes, "when persons with even very severe disabilities claim that their overall quality of life is no worse than that of nondisabled persons, there is often good reason to accept their evaluation as correct" (Brock, 2005, p. 74). Nevertheless, according to Brock, "[s]erious disabilities tend to make the achievement of some life goals more difficult or less successful and/or to significantly limit the life goals that can reasonably be pursued" (Brock, 2005, p. 72).[16]

One might wonder why Brock thinks this is the case. According to disability rights advocate Ron Amundson, the source of this belief can ultimately be traced to certain operative assumptions about biological normality, opportunity, and quality of life. In his "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics" Amundson (2005) challenges the assumptions and conceptual framework upon which Brock's (2005) argument is based. The central thesis for which Amundson's essay argues is that "an important discussion in biomedical ethics"—namely,

---

[14] Recall Robert K. Merton's (1957) notion of "pluralistic ignorance," mentioned earlier in this chapter.

[15] This success in reducing and/or eliminating the "negative impact" of disabilities, Brock suggests, can be understood at least in part as a function of a three-stage process of response to the onset of "serious" disability—namely, "adaptation," "coping," and "accommodation." (Brock acknowledges that the dividing line between "devastating, serious, and minor" disabilities is a matter of controversy. For purposes of his argument, he uses "blindness and serious mental impairment or retardation" as examples of "serious disabilities.") Citing Christopher Murray's (1996) account, Brock describes the three processes as follows:

> *Adaptation* is the process by which a person improves her functional performance through new learning and skill development. *Coping* is the process by which persons adjust and lower their expectations for functioning to reflect their lowered performance, thereby increasing their satisfaction with their level of performance. *Accommodation* is the process by which individuals adjust their life plans and activities to deemphasize or eliminate activities made more difficult or impossible by their disability and substitute activities not similarly limited (Brock, 2005, p. 73).

[16] In this context, Brock notes that some members of the disability community have challenged this claim as reflecting an (unwarranted) assumption that the "defect" is in the individual rather than the individual's environment (e.g., Silvers, 1998). He acknowledges that "[i]n many cases, much or even all of the disadvantage resulting from a disability may come from a failure to make reasonable adjustment in the social environment, adjustments that justice and equality of opportunity morally require" (Brock, 2005, pp. 72-73). Indeed, "[i]in many cases, the denial of opportunity that persons with disabilities suffer is now so comingled with stigma, social rejection, institutional discrimination, and nonaccomodating environments that it is impossible to fully disentangle the reasons for the lost opportunity" (Brock, 2005, pp. 72-73). Still, Brock insists,

> I assume that serious disabilities such as blindness and serious mental retardation will remain significant disadvantages for common human pursuits even after the goal of achieving reasonable and just social accommodation to disabilities has been reached; they are not 'mere' or solely social constructions or socially constructed disadvantages (Brock, 2005, pp. 72-73).

the discussion of "quality of life," particularly as it relates to disability—"is biased against the civil rights interests of people with disabilities because of the failure of philosophers to come to terms with the disability rights movement" (Amundson, 2005, p. 101). "Quality of life," Amundson contends, "is conceived in a way that directly conflicts with the Social Model[17] of disability, and the conflict is deeply rooted in biomedical ethical discussion" (Amundson, 2005, p. 101).

On Amundson's reading of the contemporary bioethics literature, many of those who affirm explicitly the goals of the Americans with Disabilities Act nevertheless "tacitly" assume the correctness of the medical model. One area in which this can be seen clearly, Amundson believes, is in discussions of "quality of life."[18]

In support of these claims, Amundson identifies what he takes to be the "Standard View" of disability in the contemporary biomedical ethics literature—namely, the view that "disabilities

---

[17] At the outset of his discussion, Amundson defines what he means by the "Medical Model" and "Social Model," respectively. According to Amundson,

> [a] defining characteristic of the disability rights movement is a particular explanation of the disadvantages experienced by disabled people. Disadvantages are explained as effects not of biomedical conditions of individuals but of the socially created environment that is shared by disabled and nondisabled people (Amundson, 2005, pp. 101-102).

This view, Amundson says, is typically referred to as (and is what he means by) "the Social model of disability" (Amundson, 2005, pp. 101-102). By contrast, on Amundson's account, the "traditional," or "Medical Model" view sees disability as "a problem of individuals whose biomedical conditions disadvantage them" (Amundson, 2005, pp. 101-102). On this model,

> disadvantages are natural and inevitable outcomes of simple biomedical facts. Reductions of these natural disadvantages can be accomplished only by individual cures (changing the biomedical facts) or by charitable donations intended to compensate the victims of disability for their inevitable and pitiable conditions (Amundson, 2005, pp. 101-102).

Whereas the social model pictures disability as a "problem experienced by a class of people, a problem that is caused by social organization and that can be remedied by social change" (Amundson, 2005, pp. 101-102), the medical model (on Amundson's account) is "an individualistic rather than a social theory" (Amundson, 2005, pp. 101-102). Here, "[d]isabilities are properties of individuals, and remedies (e.g., cures, rehabilitations, charitable donations) are meted out one individual at a time" (Amundson, 2005, pp. 101-102).

[18] Indeed, Amundson sets out in this paper "to show that prominent discussions of the QOL of disabled people reveal an unjustified and unexamined commitment to the Medical Model of disability and for that reason a bias against the interests of disabled people" (Amundson, 2005, p. 102). For Amundson, models of disability—including both "medical" and "social" models alike—are, in fact, actually *ideologies.* As he puts it,

> [t]he Medical and Social Models of disability are ideological, as explanations of social disadvantage often are. My claim that they are ideological amounts to the following. Each model presents an account of the causal relations that hold between disability and other phenomena. The causal accounts at first look like other causal explanations – like the gravitational explanation of the tides, for example. The causal accounts involve or entail the identification of various phenomena as *natural* or *unnatural,* and as *inevitable* or *contingent and changeable.* On closer inspection, it can be discovered that the contrasting accounts of the same phenomenon (here disability) serve or harm the interests of different groups of people. A causal account that depicts a social phenomenon as natural and inevitable (or changeable only at great cost) works to the advantage of the people who benefit from the phenomenon. When the same phenomenon is depicted as artificial and changeable, the reformist interests of those harmed by the phenomenon are served (Amundson, 2005, p. 103).

(For a discussion of the relationship between "Ideology and Etiology," see Engelhardt, 1976). The problem, in Amundson's view, comes when discussions of "quality of life" *assume,* without examination, a medical model—and hence, ideological—account of disability from the outset. The reliance upon that "unexamined assumption," Amundson argues, yields a particular "bias" against the interests of disabled persons (2005, p. 103).

Amundson's own argument is, by his own admission, based on an unargued-for assumption—namely, the correctness of the "Social Model" of disability over against the "Medical Model." Nevertheless, he believes, because the medical model is so deeply entrenched in the contemporary bioethics literature, his alternative social model approach can serve "as a critical ideological corrective to the prevailing Medical Model" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 17).

have very strong negative impacts on the quality of life of the individuals who have them" (Amundson, 2005, p. 103). This view, Amundson points out, immediately runs up against and is "refuted by" what he terms its "Anomaly": the well-documented fact that, "when asked about the quality of their own lives, disabled people report a quality only slightly lower than that reported by nondisabled people, and much higher than that projected by nondisabled people" (Amundson, 2005, p. 103). In sum, "[d]isabled and nondisabled people have very different assessments of the quality of disabled people's lives" (Amundson, 2005, p. 103).

The "Standard View" and its "Anomaly" bring the issues of epistemic standing and epistemic privilege to the fore of discussions of disability. For, as Amundson points out, "hardly anyone thinks" the Standard View is "refuted" by the Anomaly (Amundson, 2005, p. 104).[19] Instead, "[d]isabilities are so stigmatized that reports to the contrary from the stigmatized group itself are almost universally discredited or ignored" (Amundson, 2005, p. 104). How might this be explained? For Amundson, the explanation lies in the unquestioning assumption of three crucial conceptual "links" between "normality," "opportunity," and "quality of life"—represented, in turn, by the likes of Boorse, Daniels, and Brock, respectively. As Amundson sees it, "[w]ithin current biomedical thinking, the Standard View of QOL and disability is tied into a well-articulated set of views involving the notions of biological normality and the importance of a wide opportunity range for quality of life" (Amundson, 2005, p. 105). For Boorse, impairments are understood as "species-abnormal functionings," where "the distinction between normal and abnormal function is an empirically grounded implication of biomedical science" rather than "a prejudice of human observers" (Amundson, 2005, p. 105).[20]

Thus, biomedical science is (on Amundson's account of this approach) taken to ground an inference to the "objective normality of biological function" (Amundson, 2005, p. 105). From there,

> [t]he linkage from Boorse to Daniels to Brock completes an argument, apparently founded on biological fact, that people with impairments will (must?) have a low quality of

[19] To put this point in terms of the sociological literature discussed earlier in this chapter, Amundson's "Standard View" can be understood as a "schemata," one which on Amundson's view amounts to an instance of "pluralistic ignorance." See DiMaggio (1997) for discussion of schemata, pluralistic ignorance, etc.

[20] In other words, as Amundson puts it, "normal" and "abnormal" function are treated as "distinct natural kinds" (Amundson, 2005, p. 105).

> life. High QOL is dependent on wide opportunity range, which is dependent on biological normality, which is an objective fact of the natural world (Amundson, 2005, p. 105).

But each of these steps, Amundson thinks, is deeply problematic. As he puts the point,

> I believe that this chain of reasoning is flawed at every step. Boorse's contribution misrepresents biomedical science. Daniels's step embodies the prejudices of the Medical Model of disability, and so its shortcomings. Brock's contribution shares Daniels's commitment to the Medical Model, and in addition assumes an epistemologically privileged knowledge of others' lives that is unjustified by the facts (Amundson, 2005, p. 106).

The bulk of the remainder of Amundson's paper is devoted to explaining why he thinks these steps are, taken both individually and collectively, mistaken. Although his individual critiques of these three steps[21] are interesting in their own right, we will for present purposes focus only on

---

[21] Amundson's critique of Boorse's theory centers on the latter's distinction between "normal" and "abnormal" function, and the resulting notion of "normal function" that Boorse derives from that distinction (cf. the discussion of Boorse's theory, in Ch. 4 of this work). From Amundson's point of view, Boorse improperly "reifies" the "normal/abnormal" distinction in a way that "is not implied by modern biological theory" (Amundson, 2005, p. 106). [By "reification," Amundson means the process whereby a given concept—e.g., "race"—is "falsely conceived to reflect real, objective aspects of the natural world, determinable by biological science," rather than "social strategies for the management of human diversity" (Amundson, 2005, pp. 106-107). In this context, Amundson explicitly compares Boorse's alleged "reification" of the normal/abnormal distinction to the "historically reified concept of race," which Amundson says, has been "abandoned" as no longer having "scientific validity" (Amundson, 2005, pp. 106-107).] Amundson offers three reasons in support of this claim of improper reification:

> First, evolutionary biology does not imply functional uniformity as an outcome of evolution. Indeed, functional variability is a basic assumption of Darwinian natural selection. Second, the facts of developmental biology do not imply conformity among species members. Developmental plasticity and functional adaptation should lead us to expect variation, not strict conformity, in the functional organization of the bodies of species members. Third, many empirical studies of anatomical and physiological diversity in humans show a wide range of variation, too wide for a supposed 'normal range' to be neatly designated. Fourth, genetic studies of various kinds indicate enough genetic diversity in humans and most other species to allow a wide range of function, even ignoring the developmental plasticity that allows identical genotypes to divergently adapt into distinct phenotypes (Amundson, 2005, p. 106).

Amundson now turns to a critique of Daniels' argument for "the dependence of opportunity on normality" (Amundson, 2005, p. 107). On Amundson's reconstruction of Daniels' view, "abnormal function inevitably reduces opportunity range" (Amundson, 2005, p. 107). But this inference from abnormal function to reduced opportunity range, Amundson counters, "presupposes without argument the correctness of the Medical Model of disability" and, moreover, ignores a crucial distinction between *mode* of functioning, on the one hand, and *level* of functioning, on the other, relying instead on a stigma-driven view concerning "appropriate" modes of functioning (Amundson, 2005, p. 107). As Amundson puts the point,

> [t]he Social Model asserts that the opportunities lost to impaired people come from environmental design, not from biology itself. People with atypical *modes* of functioning (e.g., people who read with Braille, communicate using American Sign Language, or travel in wheelchairs) can nevertheless function at a high *level,* at least if the environment poses no obstacles to them. Nevertheless, these atypical modes are stigmatized. The assumption that unusual functional modes *necessarily* reduce one's opportunity is itself a manifestation of that stigma... (Amundson, 2005, p. 107).

In this way, Amundson contends,

> [t]he assumed 'naturalness' of the linkage of normality to opportunity harms the interests of disabled people, just as the linkage of race and sex to opportunity has been harmful to other disadvantaged groups. The claim by disability rights advocates that they are being *unfairly* discriminated against must be met head on. The notion that opportunity is *by definition* out of the reach of disabled people is rightly rejected by them, just as the same claims were rejected by women and minorities (Amundson, 2005, p. 108).

his critique of the third step—namely, the alleged link between "normal opportunity range" and "(high) objective quality of life."

With respect to this purported link, Amundson observes, the "Standard View" goes beyond Daniels' link between abnormal function and reduced opportunity to draw a further connection between "opportunity range," on the one hand, and "objective quality of life" on the other. Taking Dan Brock's views as representative of this sort of approach, Amundson first identifies what appears to be the operative assumption underlying this linkage—namely, the assumption that "unlimited major life activities are *by definition* required for a high QOL" (Amundson, 2005, p. 108). But, Amundson asks, why think *that*? For example, walking and seeing are frequently cited in the literature as "major life activities" that are essential to having a high quality of life; indeed, "[i]t might be argued that it is a matter of empirical fact that limitations in walking and seeing are associated with lower QOL" (Amundson, 2005, p. 108). But *that* claim, Amundson insists, "would require empirical data about the correlation"—data which, Amundson says, is entirely lacking in Brock's account (Amundson, 2005, p. 108).

As Amundson explains, Brock's argument turns on the distinction between "subjective" and "objective" quality of life—which distinction, Amundson says, Brock invokes in order simultaneously to "explain" the Anomaly and to "protect the Standard View from refutation" (Amundson, 2005, p. 109). On this distinction, "[s]ubjective QOL is how happy or satisfied one is with one's life," while "[o]bjective QOL is how well one's life is *really* going" (Amundson, 2005, p. 109). For Brock, "[t]o be satisfied or happy with getting much less from life, because one has come to expect much less, is still to get *less* from life or to have a less good life" (Brock, 1993, p. 309, quoted in Amundson, 2005, p. 109). It follows, then, that when people with disabilities report a high quality of life, their reports can be discounted as being "merely subjective" (Amundson, 2005, p. 109).

Brock's more recent endorsements of the Standard View have moved away from appealing to "definitional truths" (e.g., "disability defined as QOL-reducing") (Amundson, 2005, p. 110). Instead, he now typically frames the issue in terms of "*our conception of a good life,*" which conception includes "both subjective and objective factors" (Amundson, 2005, p. 110, italics in

original). Importantly, however, "the objective factors include the absence of significant disabilities" (Amundson, 2005, p. 110) as a component of "our concept" of (high) quality of life.

Amundson's initial reaction to this approach is to observe that the notion of "our conception of a good life" is rather opaque: what kinds of "evaluation standards" could or would be "appropriate to an analysis of 'our concept' of QOL"? Nevertheless, Brock himself offers an explicit argument in defense of his account, which Amundson now considers. Brock's argument uses the example of the "Happy Slave" to show that, although an individual might see himself as having a good quality of life (subjective quality of life), objectively we can still deem him to have an overall lower quality of life by virtue of being a slave (objective quality of life). The implication then is that the situation of the disabled is much the same as the Happy Slave: subjective self-perception aside, we can still say, objectively, that the disabled have a lower quality of life than the nondisabled by virtue of their disabilities. Amundson takes up this example in an effort to "examine the extent to which the Happy Slave example supports the Standard View" (Amundson, 2005, p. 110).

The Happy Slave example turns, as Amundson points out, on the distinction between subjective and objective quality of life, as well as the underlying differences in epistemic vantage points—namely, *our* "objective" epistemic standpoint versus the slave's "subjective" standpoint. In this regard, Amundson indicates that he is "willing to accept the coherence of the distinction between objective and subjective QOL as exemplified by the Happy Slave" (Amundson, 2005, p. 111). Indeed, the Happy Slave example is effective precisely because, in Amundson's words, "its epistemological credentials are built into the case"—that is, "[o]ur superior knowledge allows us to trump [the happy slave's] subjective judgments with our objective ones" (Amundson, 2005, p. 111). However, "not all judgments are made from such high epistemic vantage points" (Amundson, 2005, p. 111). When extending the Happy Slave example to other cases, such as those involving the relative quality of life of disabled persons as compared with nondisabled persons,

> the epistemic status of this kind of judgment about other people's lives is far from sturdy. The logical coherence of objective QOL is a necessary but not a sufficient condition for

> the correctness of the Standard View. In addition to proof of coherence, Brock needs evidence of *truth.* At best, the Happy Slave implies only coherence but not truth.... Separating the wheat from the chaff requires more than logic. It requires epistemology (Amundson, 2005, p. 111).

Making such judgments about the disabled, Amundson argues, requires the assumption that there is something important of which the disabled are *unaware*—that is, of which they are "ignorant"—such that their epistemic position is disadvantaged vis-à-vis that of nondisabled persons. But, he then queries,

> [w]hat ignorance burdens disabled people, and why is it so much greater than the ignorance of the nondisabled majority? Does the advocate of the Standard view really want to claim that nondisabled people *know better than* disabled people what the different lives are like? (Amundson, 2005, p. 112).

In other words, Amundson is asking, why assume *from the outset* that nondisabled persons *necessarily* enjoy a position of epistemic privilege over against disabled persons? The key question to ask, Amundson says, is this: "*when* nondisabled people claim to know better than nondisabled people what the different lives are like, why should they be believed? Why should the opinions of nondisabled people be epistemologically privileged over those of nondisabled people?" (Amundson, 2005, p. 112).

To further press the challenge, Amundson invites us to consider what he terms the "Happy Hick," as a parallel to Brock's "Happy Slave":

> People who live in rural areas are called *hicks* by some urban people who feel themselves to have superior lives. (Why would anyone give up the symphony just to breathe clean air?) The happiness of hicks is regarded as merely subjective by the sophisticates who judge them. Some of the more reflective sophisticates (some college professors, for example) might realize that their feeling of QOL superiority over hicks is not really an objective judgment trumping a subjective judgment. It is merely one person's subjective judgment clashing with another person's (Amundson, 2005, p. 112).

What this thought experiment shows, on Amundson's view, is that judgments of the sort exemplified by the Happy Slave example can, in other similarly-constructed situations, be seen to represent nothing more than "mere prejudice." This then highlights the acute need for some standard, or criterion, by which to distinguish between "mere prejudice," on the one hand, and "correct judgment," on the other.[22]

Despite this difficulty, Amundson says, the "Standard View" continues to be widely held. Why is this? Is it due to the "superior knowledge of nondisabled people about the lives of disabled people?" (Amundson, 2005, p. 113). Or, alternatively, is it "merely a reflection of the stigma of disability?" (Amundson, 2005, p. 113). In Amundson's view,

> [t]he Happy Slave has nothing to tell us. The fact that we *can* trump subjective QOL judgments with judgments *that we believe* are objective does not mean that we are correct when we do so.... In the absence of a genuine epistemological basis, it's just a conflict between subjectivities (Amundson, 2005, p. 113).

At this point it is important to reiterate what we said at the outset of this chapter—namely, that the purpose of these earlier sections is to raise, but not to *resolve*, a number of questions and issues that illustrate the ways in which various moral and non-moral normative values enter into the concepts of impairment and disability. This is especially important to underscore in the case of the Brock-Amundson debate, for that dispute involves a number of highly controversial issues the resolution of which would take us well beyond the scope of what we can accomplish here. That having been said, we can offer a few analytical comments intended to identify the crux of what would be required in order to resolve the dispute. We will also briefly preview a later section of this chapter, where we propose a possible approach to a related question, which approach might prove helpful in resolving this present dispute.

As we saw earlier, Amundson points out that the Happy Slave example turns on the distinction between subjective and objective quality of life, as well as the underlying differences in epistemic vantage points—namely, *our* "objective" epistemic standpoint versus the slave's

---

[22] As Amundson puts the point:
The Happy Slave example illustrates the coherence of objective judgments on the quality of other peoples' lives, using a plausible case of a correct judgment. But it gives us no hints about how to tell correct judgments from mere prejudices. The Happy Hick exemplifies mere prejudice in a logically similar judgment (Amundson, 2005, p. 112).

"subjective" standpoint. As Amundson notes, too, the Happy Slave example is effective precisely because "its epistemological credentials are built into the case"—that is, "[o]ur superior knowledge allows us to trump [the happy slave's] subjective judgments with our objective ones" (Amundson, 2005, p. 111). But, as Amundson goes on say, "not all judgments are made from such high epistemic vantage points" (Amundson, 2005, p. 111). This statement takes us to the crux of what would be involved in resolving this dispute. First, we must answer the question of whether or not all judgments *are* "made from such high epistemic vantage points." If the answer to *that* question is in the affirmative, then presumably Brock's position will win out. If, on the other hand, Amundson is correct in his claim that not all judgments are made from such lofty epistemic vantage points, then we are faced with several further questions. Specifically, what factors determine which epistemic vantage point will take priority? Also, when it comes to judging the quality of disabled peoples' lives, which factors are *relevant* and/or *decisive* to making those judgments? Of course, these are precisely the issues that are in dispute, which is why Brock's *prior* assumption of the priority of the non-disabled person's epistemic vantage point,[23] as well as his notion of "our conception of the good life," are problematic at best. The fact that these issues are precisely the ones that are in dispute helps to explain why debates over the quality of disabled persons' lives is so divisive and intractable

Thus, in order to settle the Brock-Amundson dispute, we first need to come to an agreement on these prior issues. But in light of the above considerations, we are now faced with the pressing question: is it even *possible* to get to an agreement on these prior issues? Here again, we will not attempt to develop a full-fledged answer to that question in this context. However, as we will see later in this chapter, the biopsychosocial approach being advanced in this work provides some useful conceptual resources for addressing these issues. By way of preview, we will in that context propose a possible solution to an apparent epistemic impasse that the "deafness" debate presents us with. As we will see, we are faced with an acute difficulty regarding whose epistemic perspective to privilege—that of the deaf person versus the hearing

[23] As we saw earlier (in our overview of Amundson's critique of Brock's position), the judgments that Brock's arguments warrant vis-à-vis the quality of disabled persons' lives require the assumption that there is something important of which the disabled are *unaware*—that is, of which they are "ignorant"—such that their epistemic position is disadvantaged vis-à-vis that of nondisabled persons. This would, ultimately, have to be Brock's central rationale for privileging the non-disabled person's vantage point over against that of the disabled person's.

person—when it comes to judgments about whether or not deafness involves a loss of intrinsic value. In that context, we will argue that, by drawing our attention to the different "levels of explanation" (biological, psychological, social, etc.) at which a given phenomenon—in this case, deafness—can be analyzed, the BPS approach advocated in this work may make it possible to reconcile what might at first appear to be irreconcilable, mutually contradictory claims. Specifically, we will suggest that depending on the *level of explanation* with which one is concerned, a different epistemic perspective might be privileged. Thus, at one level of explanation, we might privilege the perspective of the deaf person, whereas at another level of explanation we might privilege the epistemic perspective of a hearing person. We will have more to say about this later in the chapter, but for now it will suffice to suggest that this sort of approach, when generalized—and *mutatis mutandis*—may prove useful for dealing with the sorts of disputes represented by the Brock-Amundson debate discussed above.

III. MORAL NORMATIVE ISSUES

We have indicated previously that this present work will mostly bracket a full-fledged consideration of distinctively moral normative issues as they pertain to impairment and disability. This is due to both conceptual/theoretical and practical considerations. On the conceptual/theoretical side, we note that moral normative considerations appear to have more to do with questions related to the appropriate *response* to disability (however it is conceptualized), rather than with how disability itself is conceptualized. That is to say, moral normative values do not appear to enter *directly* into identification of states of affairs as impairment and/or disability in quite the same way, or to the same extent, as non-moral normative values and ontological considerations. Since the primary focus of this work is on *conceptual* issues related to impairment and disability, we have largely set aside an in-depth consideration of distinctively moral normative issues. This suggests, in turn, the *practical* reason for making this choice—namely, that a full-fledged consideration of moral normative issues as they pertain to impairment and disability would take us well beyond the scope of what can be accomplished in a single work.

All that having been said, this should not be taken to imply that moral normative considerations are *irrelevant* to impairment and/or disability, at either the theoretical or practical

levels. To the contrary, moral normative considerations play a crucial role in warranting various social policies toward the disabled, and thereby shape in important ways the character of the lifeworld in which persons with disabilities live—and this can, in turn, affect the extent to which impairments are *disabling*. So, there is a dynamic interaction between the ontological, non-moral normative, and moral normative domains (a point to which we will return later in this chapter). And, as we will see, judgments regarding appropriate social responses to disability will turn, in part, on certain prior assumptions having to do with how impairment and disability are *conceptualized*—the domain of inquiry to which this present work is devoted. Specifically, judgments regarding the appropriate social response(s) to disability will turn, in part, on two sets of assumptions: (1) assumptions regarding the link, if any, between impairment/disability and "opportunity," and (2) assumptions regarding the appropriate epistemic perspective(s) from which to judge the goodness or badness of impairments and/or disabilities (this latter issue also arose in the previous section, in the context of our consideration of non-moral moral issues, illustrating nicely how moral and non-moral normative issues are intertwined with one another). These assumptions, in turn, can lead to very different conclusions regarding the appropriate social response to disability. For example, if one assumes that disability is inherently opportunity-limiting, then this may lead to a position that emphasizes *prevention* of disability through various means, perhaps including genetic intervention and/or selective termination on the basis of disability. On the other hand, if one assumes that disability is *not* inherently opportunity-limiting, then one may be inclined to favor social polices that emphasize *accommodation* of those with disabilities, as opposed to prevention. And, of course, the question of whether or not disabilities are inherently opportunity-limiting will depend, in part, on *whose* epistemic perspective should be privileged (e.g. that of disabled versus non-disabled persons). These two sets of assumptions thus intertwine and interact with one another, though they can be distinguished logically.

By way of illustration of how these various issues come into play in discussions of the appropriate social response to disability, we will track some of the back-and-forth between the authors of *From Chance to Choice* (2000), on the one hand, and disability activist and scholar Ron Amundson (2005), on the other. For purposes of brevity, we will focus our attention here on

one aspect of that larger discussion—namely, the question of the relationship between disability and what the authors of *FCTC* term the "dominant cooperative framework."[24] As we will see, the choice of a dominant cooperative framework around which a society organizes itself significantly impacts the range of opportunities that are open to persons with disabilities. This discussion therefore helpfully illuminates the issues to which we are attending here.

Our entrée into these questions is by way of a consideration of some of the arguments advanced in chapter 7 of *From Chance to Choice,* written by bioethicists Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler (2000, pp. 258-303). *FCTC* is a prominent scholarly volume devoted to a defense of the "new genetics"—broadly speaking, the project of "improving" the human species by means of various forms of genetic intervention and enhancement (e.g., genetic engineering, prenatal genetic testing, selective abortion on the basis of genetic anomaly/defect, and so forth). In chapter 7, titled "Genetic Intervention and the Morality of Inclusion," the authors explicitly address and respond to several critiques of the "new genetics" that have been advanced by the disability rights (DR) movement. The relevance of this to our present purposes is that the discussion in chapter 7 of *FCTC* helpfully illuminates the complex relationship between the disabled and society, particularly with respect to issues concerning the "basic cooperative framework" of society.

A. Précis of *FCTC,* Chapter 7 (2000, pp. 258-303)

In chapter seven of *From Chance to Choice* (2000, henceforth referred to as *FCTC*), Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler consider the impact that the "new genetics" might have on what they term the "morality of inclusion" (pp. 258-303). By the "morality of inclusion," they mean the qualified "obligation to choose a dominant cooperative framework that is inclusive"—in particular, one that "minimizes exclusion from participation on account of genetic impairments" (Buchanan, Brock, Daniels, and Wikler, 2000, p. 20). The larger project of *FCTC* up to this point has been to consider the ethical permissibility of the use of genetic interventions—specifically, "how, when, and by whom genetic intervention technologies should be employed" (p. 258). Their discussion has thus far proceeded on the basis of a "tacit

[24] To be defined momentarily.

assumption" that "the project of using genetic science to improve human lives is not only ethically permissible but laudable" (p. 258). The authors of *FCTC* recognize, of course, that this assumption can be questioned, and so they turn their attention in this chapter to an explication and critique of what they take to be a major (perhaps *the* most important) challenge to the "project" of genetic intervention—namely, the challenge advanced by some in the disability rights movement that the "new genetics" is "exclusionary" toward (or of) those with disabilities (p. 258).

An important conceptual term employed by the authors of *FCTC* in this context is that of the "cooperative framework" (sometimes modified by "dominant" or "basic," as in "basic cooperative framework" or "dominant cooperative framework"). As the authors explain,

> [t]he term covers a wide range of structures within which cooperation can occur, from the internal organization of business firms to the most basic institutions of a society. In the United States and other "developed" societies, the most basic cooperative framework consists, to a large extent, of the competitive market system (p. 259).

The cooperative framework places specific demands upon participants in the framework, particularly with respect to their abilities and capacities. This can cause problems for those who do not possess (or cannot develop) the requisite abilities or capacities; indeed, "[w]hen a mismatch between a person's abilities and what may be called the dominant cooperative framework of society occurs, the results may be devastating" (p. 259). The implications for those who are unable to participate effectively in the "dominant cooperative framework" can be profound. Effective participation in the dominant cooperative framework can affect the extent to which an individual is able to access various "tangible social goods such as income and access to rewarding occupations" (p. 260). Moreover, exclusion from participation in the dominant cooperative framework effectively relegates one "to the inferior status of dependency" (p. 260).

Recognition of the importance of the basic cooperative framework for determining the life prospects for those who participate in that framework leads to two crucial questions related to social justice. First, who will be permitted to participate in the dominant cooperative scheme? Discussions in ethical theory of the notion of basic cooperative frameworks, these authors point out, frequently proceeds on the "simplifying assumption" that "the basic framework of society is

one in which all or most individuals who are members of the primary moral community are able to participate effectively" (p. 261), an assumption that is by no means immediately obvious. More fundamentally, we might ask this question: "How does the choice of a cooperative framework influence who will be able to participate effectively in that effort?" (p. 261). This latter question is of central importance, because "[g]iven their capacities, some individuals will be able to participate effectively in some frameworks but not in others" (p. 261). Thus, "[c]hoosing a framework for cooperation will amount to choosing who will be disabled" (p. 261).

B. The "dominant cooperative scheme" and the Deaf Culture Argument (DCA)

In a key step in their overall argument, the authors of *FCTC* insist that we can draw a meaningful distinction between "devaluing disabilities," on the one hand, and "devaluing people with disabilities" on the other. In this vein, they explain that "[w]e devalue disabilities because we value the opportunities and welfare of the people who have them. And it is because we value people, all people, that we care about limitations on their welfare and opportunities" (p. 278). Since "[w]e also know that disabilities as such diminish opportunities and welfare" (p. 278), they say, it is perfectly consistent to seek to prevent disabilities without that endeavor entailing disrespect for those persons who have disabilities. We should, ultimately, seek *both* to change negative attitudes about people with disabilities and *also* seek, through genetic interventions, to prevent the incidence (or ameliorate the effects) of disabilities in the first place—thereby achieving a congruence between the objectives of the disability rights movement and that of the "new genetics" (p. 279). Importantly, the FCTC argument at this point relies on the crucial assumption that "disabilities as such diminish opportunities and welfare" (p. 278); this constitutes a key connection between *conceptualizations* of disability on the one hand, and the putative derivation of social/political implications, on the other. Here, disability is conceptualized as necessarily implying a diminishment of opportunity and welfare, which then serves to warrant a policy of genetic intervention in order to prevent disabilities.

As might be expected, this assumption has come in for criticism, particularly from disability rights corners. For example, in the course of developing their overall defense of the "new genetics" program, the authors of FCTC consider and respond to four key DR arguments

against the new genetics. One of these, the "Deaf Culture Argument" (DCA), challenges directly the assumption that "because disabilities limit opportunity, they ought to be prevented" (*FCTC*, p. 281). Advocates of the DCA insist that deafness does not (inherently) limit opportunity, and thus there is no need to seek to prevent deafness (particularly through genetic intervention). Moreover, the claim is made that "the goods conferred by membership in the community of persons who are deaf outweighs or at least counterbalances the limitations on opportunity that deafness entails" (Buchanan, Brock, Daniels, and Wikler, 2000, p. 281).

By way of response to the Deaf Culture Argument, the authors of *FCTC* observe that the DCA is not easily generalized to the prevention of other forms of "disabling impairments" through genetic intervention (p. 281). This, they say, is because there is an "asymmetry" between "limitations," on the one hand, and "goods" on the other. On the one hand, the "limitations on opportunity" that are imposed by being deaf can be significant; indeed, absent "an enormous expenditure of social resources, the limitations imposed by being without hearing in a world in which most people hear are quite severe" (*FCTC*, p. 282). This is because "[n]ot being able to hear excludes a person from effectively pursuing many options, some of which are generally very important for most people" (*FCTC*, p. 282). So there are significant limitations that are borne exclusively by those who are deaf, as opposed to being borne throughout society generally. On the other hand, these authors contend, "the benefits provided by membership in the 'deaf community,' while important and impressive, may not in fact be available only to those who are deaf" (p. 282). That is to say, whatever benefits accrue to members of the deaf community—e.g., "solidarity" with other members of a group, or "appreciation of the uniquely expressive character of sign language" (*FCTC*, p. 282)—may *also* be available to other members of the broader society. Thus, they conclude, there is a clear "asymmetry" between the "limitations on opportunity" and the "benefits of membership in the deaf community," such that it is reasonable to seek to prevent or even eliminate deafness through genetic intervention if possible.

As these authors note, this discussion illuminates a deeper philosophical issue—namely, that of the proper perspective from which to render judgments vis-à-vis the goodness or badness of conditions such as deafness. According to these authors, "it seems that the appropriate

standpoint from which to decide whether to intervene to prevent children from being born deaf or continuing to be deaf is that of a reasonable person confronted with a choice *ex ante*" (p. 282).[25] From this perspective, they argue, it is apparent that "the fact that being deaf can bring special benefits is not a sufficient reason for one person (a parent) to choose that another, nonconsenting person (a child) should suffer this impairment" (p. 283).[26]

This discussion of and response to the DCA helps to set the stage for subsequent portions of chapter 7 of *FCTC*, which, the authors indicate, will focus on "the issue of the scope and limits of the obligation to change society to reduce the opportunity-limiting effects of disabilities" (p. 283). Their principal thesis in that context will be that "although such an obligation exists, it is a limited obligation. It is limited by the legitimate interest that persons without disabilities have in being able to participate in cooperative schemes that are suitable to their own capacities" (p. 283). (The authors of *FCTC* later refer to this as the "maximizing interest.")

Moreover, and contrary to the claims of the DCA, these authors will argue that there is a significant disanalogy between the "limitations on opportunity" that come about as a result of being deaf, on the one hand, and those that result from being black or being gay, on the other. In the latter cases (being gay or being black), "[t]he limitations a gay or black person suffers are injustices in a quite uncontroversial sense: They are forms of discrimination" (pp. 283-284). By contrast, "[w]hile deaf people and others with disabilities certainly do continue to experience discrimination, they would continue to suffer limited opportunities even if there were no discrimination against them" (pp. 283-284).[27] This latter observation, these authors believe, is of great import, for it points us back to what they take to be the central insights (and normative implications) of "the morality of inclusion." As they put the idea,

> the costs of changing society so that having a major impairment such as deafness imposes no limitations on individuals' opportunities are not so easily dismissed. Those

---

[25] Of course, one might wonder why deaf persons are not themselves "reasonable" persons whose views ought to be consulted. Does not the perspective of deaf persons matter in rendering such judgments? For further discussion of these issues, see Cooper (2007).

[26] See Merriam (2009) for discussion of some of the ethical issues related to intentionally bringing children into the world with deafness.

[27] Unless, of course, the limitations *themselves* were forms of discrimination, as social model advocates would say. As we saw in Chapter 2, disability advocate Tom Shakespeare (2006, pp. 41-42) makes a similar claim in the context of his argument against the alleged analogy between disability discrimination ("disablism") and other forms of oppression ("racism," "sexism," etc.).

> costs count from a moral point of view, because there is a morally legitimate interest in avoiding them. Understanding what this interest is and how it can conflict with the interest that persons with disabilities have in being able to interact socially without limitations on their opportunities takes us to the heart of the theory of the morality of inclusion (*FCTC*, p. 284).

For the authors of *FCTC*, then, the "morality of inclusion" (or, more precisely, the "theory of the morality of inclusion") imposes a limited obligation upon society to seek to eliminate or at least alleviate obstacles to full social interaction between persons with disabilities and the broader society. That obligation is limited by the "legitimate interest" that persons without disabilities have in avoiding the potentially significant costs involved in changing society to reduce or eliminate the "limitations on opportunity" experienced by those with disabilities.

The "limitations on opportunity" experienced by persons with disabilities is, in large part, a function of the "basic cooperative scheme" adopted by a given society. In light of this, the authors of *FCTC* articulate the DR challenge in the following terms:

> The slogan that we ought to "change society, not people" is an exhortation to modify our cooperative schemes to enable those who are now disabled to function effectively in them, rather than using genetic or other medical interventions to prevent or remove the characteristics of people that make them unable to function effectively in cooperative schemes as they are now structured (*FCTC*, p. 284).

According to the authors of *FCTC*, then, the DR "slogan" amounts to the claim that we ought to "simplify our cooperative schemes, if necessary, to make them more inclusive." There is a further implication, too—namely, that "modifying our cooperative schemes is always or at least generally morally preferable to modifying people so that their capacities better match the demands of our cooperative schemes" (p. 285).

Buchanan, Brock, Daniels, and Wikler do accept the notion that "disabilities are at least in part socially constructed," and they take this to account for "the force of the disabilities rights slogan" toward which they have been aiming their critique (2000, p. 285). Along with many social

construction theorists, these authors draw a distinction between "impairments" and "disabilities,"[28] and then go on to argue in light of this distinction that "in some cases it is not only permissible but morally preferable to modify individuals rather than the social environment" (2000, p. 285).

The distinction between impairments and disabilities is, on our authors' view, of crucial importance, for it throws into sharp relief the force of the "change society, not people" slogan that they attribute to the DR movement (p. 287). Earlier in the volume, the authors of *FCTC* developed an argument that (a) "equality of opportunity"[29] is a component of justice, (b) disabilities can limit

---

[28] Our authors offer the following definitions of impairment and disability:

- Df. 'impairment' = "By a physical or mental impairment we mean an impairment of some aspect of normal functioning for our species" (p. 285).
- Df. 'disability' = "Impairments often result in disabilities, but they need not. A disability is inherently relational: Being disabled is being unable to do something. More specifically, to have a disability is to be unable to perform some significant range of tasks or functions that individuals in someone's reference group (e.g., adults) are ordinarily able to do, at least under favorable conditions, where the inability is not due to simply and easily corrigible ignorance or to a lack of the tools or means ordinarily available for performing such tasks or functions" (p. 285).

On our authors' analysis, the key elements of this definition are three-fold. First, "someone may be unable to perform a certain range of tasks or functions but able to perform many others." Second, "disabilities are relative to a reference group." Third, "disabilities are inabilities that cannot be fixed by simply providing information or by supplying tools or means ordinarily available" (pp. 285-287). The upshot of this analysis is that

> [d]isabilities thus understood are not the same as physical or mental impairments, although impairments, if not compensated for, corrected, or prevented, can result in disabilities. Whether an impairment of the functioning that is normal for our species results in a disability depends on the social environment of the individual (p. 287).

It is in this sense that disabilities are, in part, socially constructed; "[i]mpairments become disabilities in one sort of social environment but not in others" (p. 287).

[29] Discussions of the appropriate social response to disability frequently involve some appeal to notions of "equality" at some point in the argument. These particular discussions take place against the broader background of disputes, in political and social philosophy, about the meaning and import of notions such as "justice" and what role "equality" plays in an adequate theory of justice. Typically, theories of *justice* contain, as one of their components, a theory of *equality,* including some account of how the latter concept is related to the former. Broadly speaking, the main views regarding the nature of "equality," and its relationship with "justice," can be categorized into five main types of theories—namely, "egalitarian," "prioritarian," "sufficientarian," "libertarian," and "desert" theories of equality/justice.

Egalitarian theories of equality/justice typically have one of three objects as their "target"—that is, the condition, or state, which is to be "equalized" among those to whom the respective theories apply (e.g., citizens of a particular nation or type of government, as in the "modern liberal democratic state"). These three candidate targets are "welfare," "resources," and "opportunity," respectively. Represented most prominently by thinkers such as Richard Arneson and G.A. Cohen, "welfarist" egalitarian theories seek to equalize the level of "well-being" enjoyed by each member of a given society (or nation-state). By contrast, "resourcist" egalitarian theories—famously represented by the likes of John Rawls and Richard Dworkin—seek to ensure that citizens enjoy equality in the amount of "resources" they possess and/or to which they have access. Finally, Amartya Sen and, following on Sen's lead, Martha Nussbaum have in recent years championed what (following Sen's usage) has come to be called the "capabilities approach," according to which a just society will ensure that all its members enjoy equality in their capacities, or functionings—that is, their ability to make use of the resources to which they have access, in order to pursue their goals and ambitions, or, more broadly speaking, to live a genuinely flourishing human life.

For *prioritarians* such as Derek Parfit, what matters morally is not that some people are better off than others—that is, "inequality" *per se*—but rather that some individuals may fall below a certain "minimum threshold" of well-being or flourishing. On the prioritarian view, the "priority" of justice is to ensure that the "worst-off" are made better off, or at least brought up to some specified minimum threshold of well-being, even if that means making others worse off than they might otherwise have been.

The *sufficientarian*, such as Harry Frankfurt, holds a position similar to that of the prioritiarian, but with this crucial difference: where the prioritarian will be concerned, to at least some degree, with the *amount* of disparity between the "better-off" and "worst-off" individuals, the sufficientarian is concerned only that all individuals in a given society have a "good enough," or "sufficient," level of well-being—that is, that they attain to the relevant "minimum threshold." So long as everyone has "enough," the sufficientarian is unconcerned with disparities that might exist among the "better off" and the "worse off," once everyone has been brought up to (at least) that minimum standard.

Libertarian theorists, by contrast, will have none of the foregoing. For the libertarian, represented most prominently by Richard Nozick (1974), agents "initially fully own themselves and have certain moral powers to acquire property rights in external things" (Vallentyne, 2010) subject (depending on the version of libertarianism) to certain

the opportunities that people have available to them, and therefore (c) "justice may require genetic interventions to prevent disabilities" (p. 287). The disability rights argument (encapsulated in the "slogan") under consideration here, however, directly challenges that line of reasoning. According to the DR slogan/argument,

> it is a mistake to assume that the only way or the preferable way to prevent disabilities – and hence to achieve equal opportunity – is by preventing the physical or mental impairments that result in disabilities. Instead, we can break the connection between having an impairment and being disabled – if we are wiling to make sufficient changes in our social environment (p. 287).

Buchanan, Brock, Daniels and Wikler acknowledge that there is indeed more than one way to prevent disabilities. On the one hand, one might act to prevent impairments themselves (so that disabilities do not come about in the first place); on the other hand, one might seek to alter social arrangements so that impairments do not become disabling. Nevertheless, they point out, this leaves it an open question as to which of these two means of preventing disabilities ought to be preferred over the other—that is to say, "we still need an account of why we should, as the slogan says, prevent disabilities by modifying social arrangements rather than by modifying people" (p. 287).[30]

---

constraints regarding the just acquisition and transfer of propriety, including (on some versions) requirements of compensation to those rendered unable to benefit from resources so acquired. The important upshot of libertarianism, in general terms, is that "many of the powers of the modern welfare state are morally illegitimate." Indeed, on this view, "agents of the state violate the rights of citizen (*sic.*) when they force, or threaten to force, individuals to transfer their legitimately held wealth to the state in order or provide for pensions, to help the needy, or to pay for public goods (e.g. parks or roads)" (Vallentyne, 2010). In sum, the libertarian is likely to endorse only a very limited state with limited powers to redistribute wealth and resources, for whatever purposes (whether egalitarian or otherwise).

Finally, some theorists cash out "equality" in terms of notions of *desert*. Here, the basic idea is that all citizens (members of a society, etc.) should be "equal" in the sense that they all receive shares of the social goods to be distributed in proportion to their desert—those who *deserve* more get more, those who *deserve less* get less. For a book-length discussion of "desert" theories of equality/justice, see Sher (1989).

For more on these various theories, including some helpful overviews on which this introductory material is based in part, see the following: Altman (2003), Arneson (2002a, 2002b), Daniels, (1990), Dworkin, (1981a, 1981b, 2000a-2000f), Gosepath (2006), Parfit, (1997), Engelhardt (1996), Nozick (1974), and Vallentyne (2010).

[30] According to Amundson and Tresky (2007), this attribution can be challenged. As we have seen, the authors of *FCTC* ascribe the slogan "change society, not individuals" to the Disabled Rights movement. Taken at face value, this slogan suggests that impairments should never be cured. However, Amundson and Tresky argue, this appears to be a false attribution; in fact, they claim, their research reveals that this putative slogan of the Disability Rights movement has *never* been employed by representatives of the Disability Rights movement.

Amundson and Tresky appropriately point out that this is not an official slogan of any Disability Rights organization. Nevertheless, one might wonder why the authors of *FCTC* made such an egregious error. If we assume—as some disability advocates do—that *all* the disadvantages suffered by persons with impairments result from their social context, then the various problems associated with having those impairments would stem from society rather than the individual. But, if that is the case, then all efforts *should* be made to alter society rather than the individual. Therefore, the content of the slogan, misattributed at it may be, may not be as absurd as Amundson and Tresky claim. If the authors of *FCTC* had encountered some of the literature purporting these latter sorts of claims—that is, literature advancing what we

Returning now to their own analysis of disability, the authors note that one way to think about disability is in terms of "a mismatch between an individual's abilities and the demands of a range of tasks" (p. 288).[31] This suggests a number of ways in which one might seek to achieve a better "match" between an individual's abilities (or lack thereof) and the demands of those tasks imposed upon her by her physical or social environment:

- "Changing the individual through education, training, or some other nonmedical means."
- "Changing the individual by medical means, including interventions to change her genome or to modify or counteract the effects of genes through genetic pharmacology."
- "Changing relevant features of the physical infrastructure of social interaction."
- "Changing the non-physical – that is, the institutional – infrastructure of social interaction." (p. 288)

The pertinent theoretical question can then be specified as follows: "Why should we systematically favor modes of preventing disabilities that involve changing the physical or institutional infrastructure for interaction rather than changing the individual?" (p. 288).

C. Is impairment inherently opportunity-limiting?

Clearly, a key issue underlying all of the foregoing is the question of whether or not impairment is inherently opportunity-limiting. As we have seen, the authors of *FCTC* believe that the answer to the question is yes, and their discussion proceeds on the basis of that assumption. For a different perspective on this issue, however, consider Amundson and Tresky's (2007) critiques of and rejoinders to the *FCTC* thesis

In response to *FCTC*'s claims that (1) "[e]ach individual has an important and morally legitimate interest in having access to a cooperative scheme that is the most productive and rewarding form of interaction in which he or she can participate effectively" (the "maximizing interest"), and (2) a society that integrates disabled people is not the most rewarding and productive for non-disabled people (Amundson & Tresky, 2007, p. 553, quoting Buchanan et al.,

---

have here referred to as an "unconstrained" social model—this might explain why they attributed the slogan to the Disabled Rights movement generally. Such an explanation would not, of course, excuse the fact that *FCTC* failed to cite the literature in question—and more importantly, the fact that such a "slogan" does not, as a matter of fact, actually appear in any of the literature on disability, the claims of *FCTC*'s authors notwithstanding. The content of this note is a modified version of material that appeared in Ralston & Ho (2007a, pp. 620-625).

[31] This way of putting it is reminiscent of Nagi's formulation; cf. also the Verbrugge/Jette and IOM models (see Chapter 1 for discussion of these models).

2000, p. 292), Amundson and Tresky counter with their own claim that this argument assumes that the Disability Rights movement requires that society be restructured so as to ensure that every citizen be able to perform every job. This is not the case, however: the Disability Rights movement is committed only to removing the artificial barriers that prevent persons with impairments from pursuing those jobs for which they are qualified and which they are able to accomplish. They also argue that "improvements in access increase everyone's choices, not only those who absolutely need them" (Amundson & Tresky, 2007, p. 555).[32] Therefore, they conclude, a world which integrates persons with disabilities would *not* be a world that is less rewarding or productive; it would, instead, be *more* so.

What might this sort of inclusive, integrative world look like, in practical terms? In the context of a defense of her version of the social model of disability, Anita Silvers observes that "the supportiveness, adaptability, and accessibility of the environment can have an enormous effect on whether impairment limits function" (Silvers, 1998, p. 62). As an illustration of this, she points to the case of Het Dorp, a Dutch village that was explicitly designed to be equally accessible to both mobility-impaired residents (the numerical majority) and unimpaired residents (the numerical minority). Thus, "although the majority of residents used wheelchairs, no feature of Het Dorp's adaptive design excluded unimpaired individuals" (Silvers, 1998, p. 129). This was experienced by Irving Zola, a wheelchair user, with a profound sense of "relief"—"for the first time in his life, he found himself in a built environment that welcomed rather than defied bodies like his" (Silvers, 1998, p. 129). Silvers portrays this sort of advance planning as an example of what she terms "historical counterfactualizing," that is, the process of "projecting how objective social practice would be transformed were unimpaired functioning so atypical as to be of merely marginal importance for social policy" (Silvers, 1998, p. 129).[33] Thus, for example,

---

[32] "A truly integrated society would not be simpler, as the go-fish analogy alleges. It would be more complex and more flexible. Alternative accessible means would be available for individuals to accomplish any goal that was inaccessible to them. The moderate accommodations that already exist show the value of this flexibility. Curb ramps are used by people with mobility impairments, but also by parents with strollers and workers with hand carts.

"Captioned television programs accommodate people with hearing impairments, but also assist in learning to read, in learning a second language, and in enjoying television in the same room as others who do not want the disturbance of the audio program. These examples illustrate that improvements in access increase everyone's choices, not only those who absolutely need them" (Amundson & Tresky, 2007, p. 555).

[33] Recall DiMaggio's (1997) observation that culture "constrains" by limiting people's capacities to imagine alternatives; here, the point of "historical counterfactualizing" is to facilitate the process of imagining possible alternative social arrangements with respect to the disabled.

> [w]ere a majority rather than a minority of users disabled, the initial designs of public transportation and communication systems would have accommodated them, making unnecessary the extraordinary remodeling expenditures needed to include them later on. Accommodating people with disabilities does not block access for people without disabilities, as the failure to adapt designs does for people with disabilities (Silvers, 1998 p. 130).

D. Is a "barrier-free" world achievable?

To be sure, Amundson and Tresky's claim that "improvements in access increase everyone's choices, not only those who absolutely need them" (Amundson & Tresky, 2007, p. 555) is not without potential difficulties of its own. It does seem true that, in a great many cases—perhaps even a majority of cases—the environment can be altered in such a way that both the interests of persons with disabilities and those of persons without disabilities are fully accommodated, as the Het Dorp example illustrates. There is also evidence to think that in many instances, such accommodation results in a greater or at least equal amount of productivity (Silvers, 1998, pp. 107-112). Further, it can be argued that if such alterations are not made, many talented and deserving people will not be able to enter the workforce and that society as a whole would suffer as a result (see Silvers, 1998, pp. 112-117). Nevertheless, it does seem that there may be *some* (perhaps rare) instances in which required accommodations would benefit the disabled minority at such a large cost to the non-disabled majority as to render that accommodation simply unfeasible. As Wasserman (1998) argues, the extent to which we can eliminate the inequalities attendant upon disabilities is largely a function of the degree of technological advancement to which we have attained. Thus,

> [t]he "physical capacity of the disabled" depends on available technology, which in turn depends on the resources invested in research and implementation. For example, opening doors is "beyond the physical capacity" of many disabled people, but that limitation can be overcome by electric door openers. Securing the right of people with disabilities to "live in the world" involves an indefinite commitment of resources (Wasserman, 1998, p, 180, interacting with and quoting from tenBroek, 1966).

Even so, Wasserman argues, there will always be limits to what can be accomplished by way of structural improvements: "it is not easy to see how any structural improvements could fully eliminate all... inequalities [attendant upon disabilities], and the marginal cost of further improvements is likely to increase as inequality is reduced" (Wasserman, 1998, p. 180).

There is a further difficulty—namely, what Shakespeare (2006) has termed the problem of "incompatibility." Here, the problem is that even when attempts are made to accommodate various forms of "difference" in the design of public spaces, physical infrastructure, and so forth, it may be practically impossible to accommodate every conceivable need. That is, given the variability among different types of disabilities, there may be mutual incompatibilities among different forms of accommodation: what is helpful to people with one form of impairment may pose problems for those with another type of impairment. For example,

> ...wheelchair users demand level access. Yet people with mobility issues who do not use wheelchairs may find that steps are safer and easier for them than ramps. Blind people may find that kerb cuts which liberate wheelchair users make it difficult for them to differentiate pavement from road, and leave them vulnerable to walking into the path of a vehicle. Wheelchair users may have problems with tactile paving which gives locational cues to visually impaired people.... Partially sighted people may request large text on white background: people with dyslexia may prefer black print on yellow paper. Some people will prefer rooms to be dim, others will prefer them to be brightly lit.
>
> Moreover, different people with the same impairment may require different accommodation, because everyone experiences their own impairment differently, and each impairment comes in different forms, and different people have different preferences for solving impairment problems (Shakespeare, 2006, p. 46).

In the final analysis, then, the attempt to achieve a "barrier-free world" may be literally impossible. As Shakespeare concludes:

> Implicit in the notion of a barrier-free world is the idea that Universal Design[34] can liberate all. Yet, while in each case a solution to an access barrier can be found, taken as a totality it may be impossible to create one environment which is accessible for all potential users. The principles of Universal Design are unarguable when taken separately, but may create conflict when aggregated (Shakespeare, 2006, p. 46).

Given these difficulties, it seems likely that certain "trade-offs" (to use Wasserman's term) will inevitably have to be made in seeking to find a balance between the respective needs and interests of the disabled minority, on the one hand, and the non-disabled majority, on the other. And such "trade-offs" will, of course, inevitably—and, it now appears, *rightly*—be a matter of ongoing social negotiation and political debate.

E. Some tentative conclusions/implications

In light of the discussions of the previous two subsections, we are now in a position to draw two preliminary, tentative conclusions. First, if the choice of a "dominant cooperative scheme" *determines* who will be disabled—i.e., if it shapes definitively both opportunity and outcome—then simply *defining* disability as inherently opportunity-limiting is indeed problematic, as social model advocates have argued vigorously. That having been said, this still leaves it an open question as to *how* the dominant cooperative scheme ought to be organized. Here, a second conclusion can be drawn: when it comes to finding a balance between the respective needs and interests of the disabled minority, on the one hand, and the non-disabled majority, on the other, certain "trade-offs" will almost certainly be necessary. These trade-offs, in turn, become the subject of ongoing socio-political dialogue and negotiation. We can thus give negative answers to both of the questions raised in the last two sections: on the one hand, impairment is *not* inherently opportunity-limiting; on the other hand, however, the achievement of a barrier-free world is *not* achievable. Consequently, moral normative questions regarding how we ought to respond to impairments and disabilities will retain their salience.

---

[34] Universal Design has been defined as "[t]he design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Centre for Universal Design, 1997, quoted in Shakespeare, 2006, p. 44).

IV. IMPLICATIONS FOR UNDERSTANDING 'IMPAIRMENT' AND 'DISABILITY': THE INTERACTIVE ROLE OF MORAL AND NON-MORAL NORMATIVE VALUES

Given this chapter's discussion up to this point, the key question now can be stated as follows: in light of the foregoing material, what are the *ways* in which moral and non-moral normative values play a role in identifying states of affairs as "impairment" or "disability"? In sketching the beginnings of an answer to this question, we will focus on deafness as an illustrative test case. We do so because the controversies surrounding the "deafness debate" helpfully illuminate the sorts of values that are implicated in designations of states of affairs as impairment and/or disability. More precisely, as we will see, the judgment that deafness is a disability (as well as the opposing judgment that deafness does *not* constitute a disability) relies in important and interesting ways on aesthetic, epistemic, and cultural values, as well as assumptions regarding quality of life. These values serve as grounding *assumptions* in arguments that yield different *judgments*, or *conclusions*, regarding the nature of disability, those judgments differing largely as a function of their grounding assumptions. Thus, for example, the divergent judgments 'D1 = Deafness is a disability,' and 'D2 = Deafness is not a disability' are grounded in competing aesthetic, cultural, epistemic, and quality of life assumptions. Understanding this phenomenon can, in turn, help us to grasp more clearly what is at stake in various disputes about the nature of disability and appropriate responses to it.

To preview the argument to be developed in this part of the chapter: we will use deafness as an example of how various aesthetic, cultural, and epistemic values play an interactive role in forming divergent judgments regarding disability. Disputes regarding the nature and proper characterization of deafness involve, for example, aesthetic questions regarding whether or not there are intrinsically valuable experiences, and if so, whether deafness involves the loss of such intrinsically valuable experiences. Deafness also raises important cultural issues[35]—for example,

[35] Claims to a unique cultural heritage are especially strong among advocates of "Deaf culture." In support of this claim, advocates point in particular to the possession and use of a unique language—i.e., sign language, including its variants (America Sign Language [ASL], British Sign Language [BSL], etc.)—segregated schooling for deaf persons, as well as segregated work and social environments (Tucker, 1997). The existence and use of a "distinctive, shared language" (Barnes & Mercer, 2001, p. 527) looms especially large in arguments on behalf of "Deaf culture"; such arguments frequently draw an analogy between deafness as a linguistic minority, on the one hand, and ethnic minorities on the other (Barnes & Mercer, 2003, pp. 105-106). The claim then is that both types of minority—linguistic and ethnic—are appropriately thought of as being "cultural minorities" (Barnes & Mercer, 2001, p. 527).

does it make sense to speak of a "deaf culture," and if so, what implications does that have for the question of whether or not deafness constitutes a disability? Epistemic issues play an important role in such disputes, too, particularly questions of epistemic privilege and standing. Indeed, as we will see, it can be argued that the condition of deafness presents us with a dilemma regarding epistemic privilege and standing—one that, perhaps, even leads us to the brink of an irresolvable impasse. In response to this difficulty, we will suggest that a biopsychosocial approach provides us with the needed resources to resolve this impasse, thereby vindicating once again the larger project in which this work is engaged. Finally, we will conclude this part of the chapter by considering the extent to which the deafness debate, as discussed here, is generalizable to other forms of disability.

A. The Deafness Debate

While all the domains of *non-moral normative values*—aesthetic, cultural, epistemic, etc.—are implicated in the "deafness debate," the controversy illuminates particularly well the ingression of aesthetic and epistemic values into the concept of disability. First, in the domain of aesthetic values, there is the question of whether or not there are any "intrinsically valuable experiences," and if so, whether deafness precludes the enjoyment of certain of these experiences. Those who think certain aural experiences (e.g., listening to a symphony) *are* intrinsically valuable are likely to think that deafness *is* a disadvantage by virtue of precluding those experiences, and therefore that deafness is properly thought of as a disability. By contrast, those who do not think that there are intrinsically valuable experiences, or at least not any that are precluded by deafness, are likely to challenge that characterization. Similarly, in the domain of epistemic values, the deafness debate highlights the question of who is in the best position to render judgments regarding the goodness or badness of deafness—in particular, whether deaf persons enjoy a special epistemic privilege by virtue of their unique experiential perspective, such that non-deaf ("hearing") persons cannot warrantedly render such judgments.

In support of the notion that the deaf community constitutes a distinct "deaf culture," Bahan and Parish point to the fact that the deaf community encompasses a distinct people group with a unique way of life, shared behaviors, means of interaction, belief systems, and systems of knowing/knowledge (Bahan & Parish, 2006, p. 349). In particular, according to Barnes and Mercer, "deaf culture" exhibits three major defining characteristics: (1) explicit self-referral as a linguistic/cultural minority; (2) resistance to being labeled as 'impaired' or 'disabled'; and (3) opposition to medical solutions (e.g., cochlear implants) for and genetic screening/abortion on the basis of deafness (Barnes & Mercer, 2003, pp. 105-106).

The further question, of course, is how and to what extent these aesthetic and epistemic questions/issues generalize to other forms of disability. We will return to that question later.

1. "Can it be a Good Thing to be Deaf? (Cooper, 2007)

In "Can it be a Good Thing to be Deaf?", Rachel Cooper (2007) considers the question whether it can be considered a "good" thing for someone to be born deaf,[36] by way of examining some of the specific arguments advanced by Deaf activists (who claim that it can be a good thing to be born deaf), on the one hand, and the arguments given by those who hold that it is disadvantageous to be born deaf, on the other. After arguing for the permissibility of non-deaf individuals querying whether being deaf can be a good thing, Cooper goes on to consider the foundational question of what it means for something to be a "good thing for an individual." Relying heavily on common intuitions concerning what many regard as good and bad states of affairs, she considers in turn each of the putative advantages and disadvantages associated with being born deaf, on the basis of which she seeks to render a judgment vis-à-vis the "net cost or benefit" of this condition. Cooper argues to the conclusion that it is plausible to think that being born deaf may be good for some people, but not for others.[37]

The question raised in the title of Cooper's paper—is it, or can it be, a good thing to be (born) deaf?—is an important one, Cooper notes, because it has a number of practical ramifications. For example, whether or not deaf children should be implanted with cochlear implants, and whether or not fetuses ought to be aborted on the basis of potential deafness, will turn in large part on answers to the question of the goodness or badness of deafness as such. Given these and numerous other practical upshots, the question is unavoidable. Nevertheless, it

---

[36] For reasons to be explained shortly, Cooper limits her attention to the question of the goodness or badness of *congenital* deafness, over against *acquired* deafness.

[37] This paragraph is a modified amalgam of material that appeared, in slightly different form, in Ralston & Ho (2007b), "Disability, Humanity, and Personhood: A Survey of Moral Concepts," p. 625, as well as the "Introduction" to that issue of the *Journal of Medicine and Philosophy* (Ralston & Ho, 2007a, p. 537).

Ultimately, Cooper concludes, it is "plausible" to think that "being deaf may be a bad thing for some deaf people but not for others." The decisive factor is whether, for a given individual, the advantages outweigh the disadvantages. Importantly, such advantages and disadvantages can be either "objective" (i.e., an advantage/disadvantage for the individual, independently of whether she views it as such) or "subjective" (i.e., an advantage/disadvantage by virtue of the individual's assessment of it as such). The advantages and disadvantages associated with deafness can also be either "intrinsic" (i.e., an advantage/disadvantage in any possible world) or "relational" (i.e., an advantage/disadvantage in a specific context) (Cooper, 2007, pp 579-580).

is legitimate to query whether or not this is a question that can *only* be answered by Deaf[38] people, or whether it is "acceptable" for non-deaf ("hearing") people to ask, and answer, this question. This query parallels that raised in other areas of inquiry—for example, women's studies, Black studies, and even disability studies (which, as Cooper notes, has developed separately from Deaf studies, since many Deaf activists resist being categorized as "disabled"[39]). In each of these areas of inquiry, one can legitimately ask the question whether those who are not themselves members of the group under investigation (women, Blacks, persons with disabilities) can appropriately study the group in question, or whether the members of the respective groups enjoy a uniquely privileged perspective such that only they can speak with authority to the issues raised by membership in those groups.

There are two arguments that are typically advanced by Deaf activists in support of their claim that only deaf people can legitimately ask whether or not it can be (or is) a good thing to be deaf. The first amounts to a claim of epistemic privilege. On this argument, since only deaf people can know what it is like to be deaf, they are uniquely—and exclusively—in a position to answer the question whether it can be a good thing to be deaf. The problem with this, Cooper notes, is that it renders impossible the relevant "comparative judgments" needed to answer the epistemological question. For, as she points out, when we ask whether or not it can be a good thing to be deaf, what we are really trying to find out is whether it is *better* to be born deaf than to be born hearing. And, since it is impossible for a single individual to be born *both* deaf *and* hearing, there is nothing for it but to ask *both* hearing and deaf individuals about their respective experiences. In other words, *neither* deaf people nor hearing people are uniquely positioned to answer the question—the experiential perspectives of *both* groups are needed in order to make possible the sorts of comparative judgments that are relevant to answering the query.

---

[38] As Justin Ho and I have noted elsewhere (Ralston & Ho, 2007, p. 632, note 3), it has become commonplace in the literature to distinguish between the terms 'Deaf people' and 'deaf people.' In its current usage, the former refers to those who explicitly identify themselves as a member of the deaf community; the latter refer to people who are physically deaf but may or may not consider themselves to be part of that community. See Cooper, 2007, p. 564 and Silvers, 1998, p. 32 for more on this usage of the upper-case 'D' to refer to those who explicitly identify with the deaf community.

[39] Berbrier (2002) refers to this as a "distancing" claim, where a group seeking recognized "minority" status "distances" itself from some other group—in this case, the "disabled"—that it perceives to have been stigmatized as "deviant."

A second argument—one concerned with political power[40]—is advanced by Deaf activists in support of their claim that only deaf persons can appropriately answer the question regarding the goodness or badness of being born deaf. The basic idea here is that since "knowledge equals power," claims regarding the goodness or badness of deafness amount to a political statement. Since this is the case, the argument goes, only Deaf people should be able to make such claims on their own behalf. In response, Cooper points out two problems with this argument. First, it would lead to a potentially infinite fragmentation of fields of inquiry. For example, this could support the claim that only black women can study (and write about) other black women, only white women can study (and write about) white women, only Asian women can study (and write about) Asian women, and so forth. The same would be true for other groups (racial minorities, various groups of persons with disabilities, etc.), potentially to the point of absurdity. Second, and more generally, there is the fact that the fewer the numbers of people there are working on a research problem, the less chance there is of a solution being found for that problem. This would be no less true of Deaf studies than of other fields of inquiry.

In light of these considerations, Cooper concludes that both groups—deaf and hearing people alike—are equally qualified to study deafness and the question regarding its goodness or badness. Having thus (in her view) settled the methodological question regarding who is qualified to address the question at hand, Cooper now moves to a direct consideration of the question itself. In order to answer the question, we must first get a grip on what it would mean to say that something is "good" or "bad" for someone. There are, Cooper notes, several principal ways of determining "the good" for an individual, each of which has its relative strengths and weaknesses. First, we might simply "ask actual people" what is the good for them. The problem with this approach, however, is that people often fail to know or understand what is (in fact) in their "best interests," in some cases because they are lacking essential information, in other cases because they are simply self-deceived (an all-too-common occurrence among human beings). On the other end of the spectrum, we might appeal to an "idealized standard of human flourishing" to tell us what is "good" for an individual. Here, Cooper says, the problem is that idealized standards

[40] See Berbrier (2002) and Gleason (1991) for discussion of the distinctively political aspects of groups' seeking recognized "minority" status.

are, quite simply, too "abstract."[41] Various other intermediate approaches to answering the question of "the good" for human beings have been proposed, each of which, according to Cooper, shares one or more of the problems to which the "extreme" options fall prey. At the end of the day, Cooper concludes, the best we can do is to proceed by taking stock of "common intuitions" that people have about what makes various conditions good or bad for them. In the specific context of the question regarding the goodness or badness of deafness, this means engaging in an intuitive examination of each claimed advantage or disadvantage of being born deaf, with the aim of arriving at an overall assessment of the relative goodness or badness of that condition.[42]

At this point, Cooper pauses to consider two "easy" approaches to answering the question that, ultimately, "will not work." The first of these is to simply question deaf people themselves. But this, of course, runs into the problems we saw above. In order to show why this is the case, Cooper reminds us of the distinction between being *born* deaf (congenital deafness), on the one hand, and *becoming* deaf (acquired deafness) at some later point in time. Clearly, or at least presumably, an individual who *becomes* deaf will experience this as a serious loss—she has, after all, learned first to live in a "hearing" world" and now must learn to cope with living without the sense of hearing. By contrast, the person who is congenitally deaf is in a very different situation—in her case, she *never had* the ability to hear in the first place, has developed various strategies for living without auditory input, and so may very well *not* experience her deafness as a *loss.* For that individual, it may not make sense to say that being deaf is "worse" than being hearing, for all she has ever known experientially *just is* being deaf. The relevant question for our purposes, then, becomes this: is it better (or at least equally good) to be congenitally deaf than to be congenitally hearing? Is one way of living actually *better* than the other? At this point, the difficulty should be obvious: it is impossible for a single individual to answer that question, at least

[41] As Cooper puts it, "appeals to 'ideal standards of human flourishing' seem disturbingly abstract. It is not clear how the ideal standards are fixed, nor is it clear how we can find out about them" (2007, p. 567). Ultimately, "idealized-standard" approaches run into an epistemic problem: since none of us is actually "ideal," how can we know what an "ideal" person (or an idealized version of oneself) would choose? On the other hand, "actual-person" approaches run into the difficulty that people routinely make errors about what is good for them.

[42] Interestingly, Cooper nowhere provides a rationale for thinking that this *intuitive* approach will be any more reliable than the other approaches she has already rejected. It is worth at least asking the question: why think that the intuitive approach will be any *more* successful than the other approaches?

on the basis of personal experience alone, for, as previously noted, no one can both be born hearing and born deaf.[43]

Another "attempted easy answer" that, on Cooper's view, "will not work," is that of appealing to "the natural" to determine whether deafness is a good or bad condition for an individual. In particular, claiming that deafness is a "dysfunction" will not settle the question of its goodness or badness. This is because, on the one hand, conditions that are biologically "natural" in the sense of "conferring a selective advantage" may nonetheless be bad for the individual with the condition—indeed, the condition may very well have been selected for precisely because it contributes to the organism's "inclusive fitness." Thus, there is no necessary connection between being "biologically natural" and being good for an individual organism. On the other hand, there may be conditions that are biologically dysfunctional but that are not "bad" or "harmful" for the individual who has that condition (Cooper points to homosexuality as a possibility here). The upshot of all this is, according to Cooper, that there is no necessary connection between proper biological function and "being in a good state." Consequently, she concludes, "asking whether deafness is a biological dysfunction will not help determine whether it is a bad thing to be deaf" (Cooper, 2007, p. 570).

If these apparently "easy" approaches will not suffice for answering the question at hand, then the only alternative is to examine and assess, in turn, each of the putative advantages or disadvantages of being deaf. To this task Cooper now turns. First, she considers the "absent qualia argument," which claims that deafness is a bad condition because deaf people miss out on qualia that hearing people experience, particularly qualia that hearing people find intensely pleasurable. In response to this, Cooper argues, first, that simply having *more* qualia is not necessarily better than having fewer—indeed, she says, "there are no senses that are necessarily a blessing" (Cooper, 2007, p. 571). Instead, the value of the various senses, including the ability

---

[43] Cooper intends this to support her claim that Deaf people are not in an epistemically privileged position to answer the question regarding the goodness/badness of deafness. On the face of it, I am inclined to agree. However, if it is *literally* true that the question is *impossible* (for any single individual) to answer, then this would seem to support an even stronger claim—namely, that the question shouldn't be asked *at all,* which would appear to shut down the conversation altogether. And that would seem to be a rather odd consequence of this claim. Perhaps, then, we should conclude not that the question cannot be answered at all, but that it cannot be answered *merely* by appeal to subjective opinion. Perhaps, in other words, we cannot get away altogether from appeal to some sort of "objective" or "idealized standard" of human flourishing after all.

to hear, is context-dependent; we could imagine possible worlds in which, for example, the sense of smell would be bad for those who have that sense.[44] In certain environments, there are few pleasant sound qualia for deaf persons to miss out on in the first place—for example, "[i]f one lives in a flat between a railway and a school, with neighbors who play novelty pop records at full volume over and over again, then it may very well be the case that not hearing noise qualia is a benefit" (Cooper, 2007, p. 571). Finally, Cooper points out, deaf people experience *different* qualia than do hearing people, so the mere fact that they miss out on qualia experienced by hearing people does not necessarily mean that they are disadvantaged relative to hearing people.[45]

Another major area of dispute regarding the goodness or badness of deafness revolves around the question of language—specifically, whether sign languages are inherently inferior to spoken languages, in which case deaf people would be uniquely disadvantaged vis-à-vis their hearing counterparts. This is because many deaf people are unable to learn or utilize the (spoken) languages employed by non-deaf (hearing) populations; consequently, many deaf persons are limited to using only sign language—in which case, *if* sign language is inherently inferior to spoken languages, then deaf persons are disadvantaged by virtue of being deaf. If this is so, then deafness would appear to be a bad thing for those individuals who have that condition. In response to this line of reasoning, some Deaf activists have argued that, in fact, Deaf people simply have their own form of language, which language is "equally good" as those used by other populations; therefore, they conclude, whether or not deaf persons are able to learn other languages is irrelevant to the question of the goodness or badness of deafness as such.

This dispute highlights issues of commensurability at a number of levels—in particular, between (1) sign languages and other languages, and (2) Deaf cultures and other cultures. Regarding (1), the key conceptual issue is what it means to say that languages are "equally

---

[44] As Cooper puts it, "[i]f pollution increases significantly in the coming years, then come, say, 2050, people who lack a sense of smell may come to be considered unusually fortunate. When the only smells are nasty, lacking smell qualia is not a bad thing" (Cooper, 2007, p. 571).

[45] Cooper states that "people who are deaf from birth experience qualia that hearing people do not. Deaf people may become more sensitive to vibrations and to visual stimuli than are hearing people..." (2007, p. 571, citing Bavelier et al., 2000). It would seem, however, that being "more sensitive" to certain qualia (vibrations, visual stimuli, etc.) is not necessarily the same thing as *having* or *experiencing* qualia that others do not. Might it be possible for hearing people, with the appropriate training, to become "more sensitive" to such qualia as well? This is, of course, an empirical question that cannot be answered here.

good." In this regard, Cooper observes that the claim that sign languages are "equally good" as those languages used by hearing persons amounts to the claim that these languages are equally good for expressing *ideas*. But if, as Cooper contends, language shapes thought, and if some languages lack the resources needed to express certain thoughts, then it follows that some languages are able to bring about a greater range of thoughts—hence, *ideas*—than others, and thus not all languages are "equal." What this means, in practical terms, is that comparison of sign languages versus spoken languages is an *empirical* question, with a view toward determining which of these languages is better equipped for communicating ideas. Importantly, Cooper argues, this also means that there is no *a priori* justification for the claim that sign languages are "equal" to other languages. This is significant, for the relative "richness" or "poverty" of a given language can affect an individual's ability to communicate with other human beings, and even her ability to form thoughts. Consequently, the relative richness or poverty of sign language is of direct relevance to the question regarding the goodness or badness of deafness (i.e., whether being deaf is advantageous/disadvantageous). In this regard, Cooper argues, there is an important asymmetry between sign language (SL), on the one hand, and spoken languages, on the other. Specifically, she says, if SL is a poorer language, then this is a disadvantage of being deaf. However, if SL is a richer language, this is *not* an advantage of being deaf. The reason for this asymmetry is that whereas hearing people can (relatively easily) learn sign language, many deaf people are unable to learn to speak orally (or can do so only with great difficulty); consequently, there is disadvantage inherent in deafness that is not shared by the hearing population. There is thus an asymmetry of advantages versus disadvantages of being deaf versus being hearing, at least with respect to differences in language.

There is, according to Cooper, a further (slight) disadvantage of being deaf—namely, being limited to a smaller linguistic community, and thereby being limited to a smaller range of human interaction. It is, Cooper avers, a "slight" disadvantage "to *have* to belong to a small community even if one likes small communities" (Cooper, 2007, p, 576). This is because "[i]n general it is a good thing to have worthwhile opportunities, even if one does not presently want to take advantage of them" (Cooper, 2007, p. 575).

Given the disadvantages of deafness just discussed, the obvious follow-up question is what should be done about them—which returns us to the *moral normative* domain. Here, Cooper argues that the answer to that question is largely context-dependent. On the one hand, in the famous Martha's Vineyard case, an unusually large deaf population on the island eventuated in a situation in which non-deaf residents also learned sign language, so that communication between hearing and deaf persons was facilitated and became largely unproblematic in that context. On the other hand, Cooper invites us to imagine a (hypothetical) scenario in which, thanks to advances in medical and other technologies (including, e.g., widespread use and easy availability of cochlear implants and/or genetic engineering to reduce the incidence of deafness), there was only one deaf person remaining in society. In such a world, would the dominant hearing population be obliged to learn sign language in order to facilitate communication with that one individual? Or, in such a case, would it make more sense to "alter" that individual (e.g., by use of a cochlear implant) in order to make communication possible? Cooper's intuition regarding this hypothetical case is that the latter solution would be warranted rather than the former. The point of this thought experiment, however, is simply to illustrate Cooper's larger point that "communication problems" of this sort can be thought of as "relational problems"—that is, they are problems caused *both* by a condition inherent in the individual (her deafness) *and* by a condition inherent in society (the majority population is hearing rather than deaf, they do not know sign language, and therefore they cannot communicate with the deaf individual). Such a "relational problem," Cooper points out, can be solved *either* by altering the individual (cochlear implants, genetic interventions, etc.) *or* by altering the surrounding society (having everyone learn sign language)—and there is no *a priori* reason to prefer one over the other.

The significance of this observation, on Cooper's view, is that it highlights an important fact that is often overlooked in the debates over deafness, in particular, and disability in general—namely, that causal claims regarding deafness or disability are themselves *political claims*.[46] That

[46] "Those who adopt social models of disability claim that the source of disabilities lies in society rather than in the individual and that society should change to fix the resulting problems. To take an example, those who adopt a social model of disability commonly claim that people in wheelchairs are disabled not by their inability to walk, but by a society that builds stairs. I suggest that this claim should not be understood as a purported description of fact, but rather as a political claim. In themselves, the problems faced by wheelchair users are relational. They can be fixed either by enabling the wheelchair user to walk or by changing the material environment. When the social model of disability claims that

is, the claim that "disability is caused by X" amounts to a political claim regarding *what ought to be changed*—either society or the individual—in order to "fix" the problem.[47] But the answer to the question, "what ought to be changed in order to fix the problem of disability" is, Cooper insists, a "highly contingent" one—depending, among other factors, on the practical feasibility of making the relevant changes (is it even *possible* to change either society or the individual in this case?), the degree of difficulty involved in making such changes (what are the respective costs involved), as well as the historical antecedents of the problem itself (e.g., can the problem be traced to specific instances of societal discrimination?). In many cases, it will be plausible to insist that society ought to change; in other cases, it may be more reasonable to conclude that the individual ought to be changed. There is, however, no *a priori* reason for preferring one over the other.

2. Critical analysis

It is worth noting in this context that in her response to the "absent qualia" argument, Cooper focuses entirely on the issue of *quantity* of senses/qualia. That is, she argues that no senses are necessarily a blessing, and that having *more* qualia is not necessarily better. But this, it would seem, misses the issue of *quality*—that is, the *qualitative* question of what it is that deaf people miss out on. The claim is that hearing people experience certain *qualitative* features that are missed by deaf persons—e.g., the *qualitative* experience of listening to a symphony. As we have noted, some will argue that such a qualitative experience is *intrinsically* valuable in its own right, such that *not being able* to listen to a symphony is, in itself, a disadvantage. This would seem to be a separate issue than the question of whether all the senses are necessarily a blessing, and/or whether having a greater number of senses (or qualia) is necessarily better. Hence, it seems that we could grant Cooper her points about the individual senses not always being a blessing, as well as her claim that having more qualia is not necessarily better, while at

---

society causes disabilities this should be understood as a political claim asserting that society, and not disabled individuals, should change in order to solve the problems faced by disabled people" (Cooper, 2007, p. 578).

[47] As Cooper puts it, "...whether a problem is thought of as being caused by the individual's condition, or by society, depends on the politics of the situation.... the difficulties are relational—in the sense that they could be solved either by changing society or by changing the individual. However, when we think that the individual *should* change (if he or she can) we tend to locate the problem as being 'in' the individual... In contrast, when we think society should change, we locate the problem elsewhere" (Cooper, 2007, pp. 577-578). Cf. the intrinsic/extrinsic and 'present in'/'said of' distinctions, discussed at various points throughout this work.

the same time insisting that it is a *disadvantage,* in and of itself, to be *unable* to undergo an intrinsically valuable qualitative experience such as listening to a symphony.

We can press these concerns even further. Upon reflection, it would seem that there is at least one respect in which the hearing person is, at least *prima facie*, in an epistemically privileged position vis-à-vis the (congenitally) deaf person. Specifically, whereas the congenitally deaf person must imagine or infer what it would be like to hear (or gain the sense of hearing), the hearing person (by contrast) knows, by direct acquaintance, *what it is to hear* and thereby also has a keener sense (in comparison to the congenitally deaf person) of what the *loss* of that ability would entail. While a thorough defense of this claim is beyond the scope of this present work, it seems plausible on its face. And if it is correct, then there may be grounds after all to claim that the hearing are in a better position, epistemically speaking, to render an evaluative judgment regarding the goodness or badness of deafness *as such*. (We will consider an objection to this claim later in this chapter.)

In order to avoid misunderstanding, several qualifications to this claim are in order here. First, the claim that hearing people may be in a better position, epistemically speaking, to render a judgment vis-à-vis the goodness or badness of deafness *simpliciter* is, of course, very different than rendering an evaluative judgment about the life, *taken as a whole*, of an individual who is deaf—a negative judgment regarding the former need not entail a negative judgment regarding the latter.[48] Second, whether the condition of being deaf makes possible *other* goods not experienced (and, perhaps, not capable of being experienced) by hearing people, is yet another question—one which, arguably, deaf people may very well be in a better position (epistemically or otherwise) to answer. Still, even if one does think that such goods exist, or that they counterbalance the (putative) disadvantages occasioned by the condition of deafness, this is nevertheless consistent with the possibility that there may be certain respects in which hearing people are in an epistemically privileged position vis-à-vis deaf people.

Before proceeding further, a final analytical observation is in order here. A hinge question in all these considerations will be whether deaf people miss out on major cultural dimensions—

[48] Cf. the discussion in Ch. 4 of the "disadvantage vs. disadvantage on balance" and "trait vs. person" distinctions.

e.g., music—for which there is no adequate compensation. Here, it is important to distinguish between two different senses of "compensation." In one sense, an individual with sensory loss such as deafness is "compensated" for that loss by the fact that she develops (or is given, perhaps by a divine agent; cf. the discussion of the moral model approach, in chapter 2)—a different or additional faculty in lieu of hearing (e.g., being able to see or hear things that others cannot; being more sensitive to other stimuli/input; divine compensation with special insight, etc.). Contrast this sense, on the one hand, with another sense of the term—namely, cases in which the individual in question (in this case, the deaf person) is *given something by society* (e.g., financial resources, cochlear implants, etc.) in order to "compensate" for her deafness and/or the disadvantages associated with that condition. We might call the former sense "adaptive compensation," and the latter sense "social compensation." The key point, for present purposes, is to note that in asking the question whether deaf persons miss out on certain dimensions of experience—e.g., cultural dimensions conveyed through music—for which there are no adequate forms of compensation, this is ambiguous with respect to which sense of "compensation" is being referred to. Thus, it is perfectly consistent to claim that deaf persons miss out on features of experience for which there is no adequate compensation in one sense (e.g. adaptive compensation), while affirming that "compensation" can be made in the other sense (e.g. social compensation)—or vice versa.

B. Does the Deafness Debate Generalize to Other Forms of Disability?

In light of the foregoing, there seem to be at least three respects in which the "deafness debate" is generalizable to other forms of disability. First, as we saw, there is good reason to think that there may be a significant lack of epistemic parity between those who are congenitally deaf and those who are congenitally hearing. Given their knowledge-by-acquaintance of what it is to hear, members of the hearing community would seem to be at an epistemic advantage vis-à-vis those in the deaf community, in at least one respect—namely, having a keener sense of what the loss of the faculty of hearing entails. By contrast, congenitally deaf persons might perhaps be able to *imagine* what it would be like to hear, but they would seem to be limited to imagination rather than knowledge-by-acquaintance. Arguably, we might make similar sorts of claims about

other forms of congenital disability; if such claims go through successfully, then the "deafness debate" will be generalizable in this respect.

Second, the deafness debate is arguably generalizable to other forms of disability in its illumination of the nature of disability as a "relational problem." Here, the basic idea is that just as deafness can be seen as presenting "relational" problems of communication, so it might turn out that other forms of disability can be seen as posing "relational" problems of other varieties (e.g., relational problems of mobility).

Finally, there is the issue of the *political* nature of causal claims with respect to disability. As we saw, the claim that the problems faced by deaf persons is *caused* by society rather than their bodies (or vice versa) amounts to a political claim regarding who or what should be changed in order to correct the problem. Arguably, if this notion is correct regarding deafness, we might also say something similar about disabilities more generally.

Having laid out, in general terms, several ways in which the deafness debate appears to be generalizable to other forms of disability, we must now consider an objection that has potential to derail the argument. Crucially, the above comments regarding deafness were made with respect to *congenital* rather than *acquired* deafness. Matters appear to be more difficult, however, when we move away from comparing only *congenital* deafness with *congenital* hearing. Consider, for example, those with *acquired* deafness—that is, those who once were hearing but *now* are deaf. What are we to make of their claims—when such claims are made—that being deaf is as good as, no worse than, or even better than being hearing? After all, these people *do* know "both sides of the equation," so to speak—they have experienced *both* being hearing *and* being deaf. Prima facie, it would seem that in *these* sorts of cases, we ought to defer to the person with acquired deafness and grant her epistemic privilege with respect to such judgments. But then, if we grant this with respect to those with *acquired* deafness, why should this claim hold true only for *them*—that is, why would it not *also* be true of those with congenital deafness as well? After all, the judgment in question is that *deafness* as such is "as good as, no worse than, or even better than" being hearing—and why should the truth value of *that* judgment depend on the amount of time for which one is, or has been, deaf (i.e., acquired later in life versus being born

with the condition)? So perhaps the deaf person's perspective *always* trumps that of the hearing person, after all. But if that is the case, then we seem to be faced with two equally compelling choices—*either* privilege the hearing person's perspective *or* privilege the deaf person's perspective—both of which seem to enjoy *prima facie* plausibility. But which one should we affirm, and on what grounds?

Perhaps we need to distinguish between two different sets of circumstances, arguing that the epistemic disparity goes in different directions in each case. The idea here would be as follows. In cases where we are comparing *congenital* deafness with *congenital* hearing, we should (for the reasons discussed earlier) grant epistemic privilege to the *hearing* person's perspective vis-à-vis the loss involved in deafness. Thus, if the hearing person is at an epistemic advantage versus the congenitally deaf person, then this would seem to favor the hearing person's opinion regarding whether or not deafness involves a loss of intrinsic value. On the other hand, if we are comparing the perspectives of an individual with *acquired* deafness with that of a congenitally hearing person, it would seem that (for reasons just discussed), we should grant epistemic privilege to the perspective of the person with acquired deafness. Here, if the person with acquired deafness is in an epistemically privileged position, then *her* judgment regarding whether or not deafness involves a loss of intrinsic value would seem to take priority. But, then, we are left with an obvious difficulty: in one case, the judgment that deafness *does* involve a loss of intrinsic value is affirmed; in the other case, that same judgment is denied. On pain of contradiction, this claim cannot be *both* true *and* false, in the same way at the same time—but how are we to adjudicate between these two judgments, both of which appear to be (for reasons given above) plausible on their face? Are we left, at the end of the day, with a brute "conflict between subjectivities" (to borrow Amundson's phrase; see Amundson, 2005, p. 113)?

It would appear, then, that we are at a potentially irresolvable impasse. Before proceeding to suggest a possible way of getting beyond this impasse, two observations are worth making here. First, this discussion underscores the point we made earlier about the importance of the variability of types of disability—in this case, the distinction between a congenital and an acquired disability has the potential to warrant very different judgments regarding the nature of

disability. (Whether it will ultimately be necessary to go that route remains to be seen; the point for present purposes is simply that the variability of disability opens the door to this possibility.) Second, this discussion also puts into stark relief one reason why many disputes about the nature of disability can become so acrimonious and intractable: they are, in many cases, being advanced from the standpoint of very different epistemic vantage points.

So, *can* this apparent impasse be resolved? As a tentative suggestion in this regard, it would appear that a biospychosocial approach of the sort being developed in this work may very well provide us with the resources needed to bridge the divide between these different perspectives. The general contours of such an approach can be outlined in the following way. A biopsychosocial approach to disability will affirm that there are different *levels of explanation* at which deafness can be (correctly) characterized. At the biological level, we can say that a real loss has occurred—namely, a loss of biological, anatomical, or physiological function. Socially, too, a real loss has occurred: namely, missing out on aesthetic experiences to which others have access. Psychologically and psychosocially, however, deafness may or may not be experienced as a loss, depending on social responses, available social supports and/or environmental modifications, and so forth. The respective epistemic standpoint that is privileged differs depending on which level is being addressed: at the biological level, the perspective of relevant medical/scientific professionals is privileged; at the social level, the perspective of those who know "both sides of the equation"—that is, either the congenitally hearing person or the person with acquired deafness—is privileged; and at the psychological and psychosocial level, the perspective of the individual with the condition (i.e., deafness) is privileged. There is a sense in which we are, in effect, saying that *everyone* is "correct" in this case, that *everyone's* epistemic perspective should be "privileged." However, there is a key difference between the scenario that generated the "impasse" to which we are responding, and the approach we are now proposing as a solution: here, the different persons are actually making *different claims* about *distinct levels of explanation*—i.e., (1) "*at the biological level*, deafness does/does not involve a loss of intrinsic value," (2) "*at the psychological/psychosocial level*, deafness does/does not involve a loss of intrinsic value," and (3) "*at the social level*, deafness does/does not involve a loss of intrinsic

value," etc.—rather than making mutually contradictory claims about the *same* proposition, namely, (4) "deafness does/does not involve a loss of intrinsic value" (where that proposition is not further specified with reference to the level of explanation).

This is, of course, a cursory sketch of what such an approach might look like, and without further development it does not us (yet) provide us with sufficient resources to offer concrete action guidance (i.e., how to respond to disability); a thorough development and defense of these statements would, however, take us beyond the scope of this present discussion. The main point for present purposes is to suggest that a biopsychosocial approach to disability provides us with fruitful theoretical and conceptual resources for dealing with difficulties such as that raised above. We might also generalize this approach, *mutatis mutandis,* to address other related difficulties, such as the Brock-Amundson dispute discussed earlier in this chapter. For example, drawing on the approach sketched here, it might be open to us to argue that Brock and Amundson are in fact making claims with respect to different *levels of explanation.* If so, then we may be able to develop an argument that the disabled person's epistemic vantage point ought to be privileged at one level of explanation, whereas the nondisabled person's perspective ought to be privileged at another level of explanation, and so forth. To be sure, this does not yet *resolve* the Brock-Amundson dispute, but it does suggest a possible strategy for moving toward a resolution. In short, the basic idea is that, at different levels of explanation, the different judgments regarding "quality of life" may, in fact, be "correct," in the sense that they accurately capture the reality *at that level of explanation.* The further question, of course—one which would take us beyond the scope of the present work—is how to move from each of these *individual* assessments (at the biological, psychological, and social levels, respectively) to an overall, "all-things-considered" judgment regarding the quality of disabled person's lives. Interestingly, however, it is worth noting that the biopsychosocial approach advocated here helps to underscore the reality that "quality of life," as with concept of "disability" itself, is a complex phenomenon, one that involves a number of different dimensions, each of which can be explained at a different level of explanation, and which interact with one another in complex ways. This suggests, in turn, that on a biopsychosocial approach, the "quality of life" question is initially left as an "open question"—change one of the

variables (e.g., the "biological," "psychological," or "social" realities of the lives of disabled persons), and you may, in turn, change the overall, "all-things-considered" judgment regarding quality of life. In this way, the biopsychosocial approach directs our attention once again to the sorts of ongoing sociopolitical factors, among others, that affect the contours of the lifeworld of persons with disabilities.

V. CONCLUSION/SUMMARY

The overall objective of this chapter has been to show how various non-moral and moral normative considerations enter into identifications of states of affairs as impairment and disability, and how they interact with one another. We approached this task by way of asking two key questions: (1) first, what role should *non-moral normative* considerations be understood to play in identifications of states of affairs as "impairment" or "disability"?; and (2) second, what role do *moral normative* considerations play in our conceptual understanding of impairments and disabilities, on the one hand, and in judgments regarding appropriate social responses to conditions so labeled, on the other?

In response to the first of these questions, we identified three key domains of non-moral normative values or concerns that enter into identification of states of affairs as impairment or disability—namely, aesthetic, cultural, and epistemic values or concerns—and discussed in each case some of the issues that are at stake in each of these domains.

Following on this exploration of relevant domains of non-moral normative values, we went on to consider some key moral normative considerations that pertain to our understanding of and responses to states of affairs identified as impairment and disability. Among other topics, we paid special attention to the relationship between how disability is conceptualized, on the one hand, and what one takes to be the appropriate social response to disability, on the other. In this context, we considered the question of whether or not disability is appropriately conceived of as being inherently opportunity-limiting. Here, we concurred with many disability rights activists and scholars in concluding that, in fact, disability is not *inherently* opportunity-limiting. Nevertheless, as our discussion showed, it is also apparent that an *entirely* "barrier-free world," in which those who currently experience limited opportunities due to what are deemed to be "disabilities" no

longer experience any limitations on their opportunities, is simply unachievable, both practically and conceptually speaking. Consequently, "trade-offs" will be necessary: the relationship between the disabled and the broader society will inevitably be a matter of ongoing sociopolitical negotiation.

Connecting this chapter's conclusions with a point discussed in the previous chapter, it is worth noting that if, as we saw in chapter 4, the concept of disability inevitably involves *relational* predication—that is, a combination of features intrinsic to the individual and external to her, or (to put it in slightly different terms) a combination of intrinsic and extrinsic predication—then it makes sense that when it comes to the relationship between the disabled and the broader society, disability is best thought of as what Cooper (2007) refers to as a "relational problem" (see Part IV of this chapter for further discussion). With this thought in mind, Chapter 7 concludes our exploration of the concept of disability by exploring, in a tentative and preliminary fashion, some of the potential implications of this work for our understanding of disability, the future of the disability studies and disability rights movements, and for the relationship between the disabled and society generally. Meantime, however, Chapter 6 engages in a further, more detailed exploration of some of the pertinent sociological and political issues that are implicated in the debates over the nature and proper conceptualization of disability.

Chapter 6

THE CONCEPT OF DISABILITY: SOCIOLOGICAL AND POLITICAL ISSUES

I. INTRODUCTION

This chapter addresses an important issue that has come up repeatedly throughout this work, especially in Chapter 5—namely, the issue of *stigma.* The medical model has been repeatedly charged with *stigmatizing* the disabled and has been rejected by the DR movement because of that charge. It is important to understand (a) *why* the charge is made and (b) what is the social-political significance of the charge. Further, it is necessary to consider whether that charge is sufficiently strong enough to undermine or even derail the larger project in which this work is engaged, and to consider whether or not the concerns expressed in this charge can be addressed. These are some of the issues to which this chapter attends. In effect, the purpose of this chapter is to buttress against a potential objection to the project in which this work is engaged—namely, developing a biopsychosocial approach to disability, one which *incorporates* the insights of the medical model, but does not reject that model altogether, as do advocates of the social model. Advocates of the social model would say that the medical model is fatally flawed because of its "stigmatizing" effect; if so, then that same charge could potentially be leveled at *this* project as well—the idea being that, by incorporating aspects of the medical model into the BPS account, we are, in effect, stigmatizing the disabled. So, it is important to see if an answer to that charge can be found.

The chapter proceeds as follows. First, we set forth some of the relevant sociological literature on culture and minority status claims, with a view toward showing what is at stake in disputes about stigmatization and the status of the disabled in society (i.e., "deviant" versus "minority" etc.) and to demonstrating what claims to minority status on behalf of various groups (e.g., the disabled) amount to. Next, we move on to a direct consideration of stigma itself, with particular focus on the notion of "disability stigma" and some of its possible causes. In this regard we consider whether, in fact, the medical model *is* guilty as charged—that is, guilty of stigmatizing the disabled. After advancing a preliminary answer to that charge, one which seeks to vindicate

the project in which this work is engaged, we move on, in the final sections of the chapter, to a brief consideration of the prospects for preventing stigmatization of the disabled, and to suggest some ways in which this project's "biopsychosocial" approach to disability might be helpful in that regard.

II. THEORETICAL BACKGROUND: CLAIMS TO "MINORITY" STATUS—INSIGHTS FROM THE SOCIOLOGICAL LITERATURE

A. *Why* do groups make claims to minority status?

In an article titled "Minorities (Almost) All," Phillip Gleason (1991) traces the historical development of the concept of "minority" in the context of American social thought. He notes that the "conventional sociological sense" of the term, in which it carries the connotation of a "subgroup" of a population, did not come into widespread currency until relatively recently. Previously, the term had been used with other connotations, for example, to refer to those not yet of legal age (e.g., "in her minority") or, in a European context, to refer to separatist *nationalist* movements. Only in the second half of the twentieth century did it come to be used with a distinctively *numerical* connotation, to refer to a subgroup of a population.

This new sense of the term 'minority' is reflected in the 1961 edition of *Webster's III* dictionary, which included, among others, the following definition: "a group differing from the predominant section of a larger group in one or more characteristics (as ethnic background, language, culture, or religion) and as a result often subjected to differential treatment and esp. discrimination..." (Gleason, 1991, p. 392). In the American context, this sense of the term gained rapid acceptance; it was

> absorbed into the vocabulary of New Deal liberalism as applied to group relations and was associated with emphasis on the analytical importance of the culture concept, acceptance of cultural pluralism as a social ideal, and with the rejection of nationalism, ethnocentrism, and prejudice as group norms or personal attitudes (Gleason, 1991, pp. 395-396).

In the sociological literature, the term (in its contemporary sense) was initially introduced by Donald Young in 1932, and given its "classic elaboration" by Louis Wirth (Gleason, 1991, p. 394, 398). As Wirth defined the term, a *minority* is "a group of people who, because of their physical or cultural characteristics, are singled out from the others in the society in which they live for differential and unequal treatment and who therefore regard themselves as objects of collective discrimination" (Wirth, 1964, pp. 245-47, quoted in Gleason, 1991, p. 398). Additionally, according to Wirth, the minority is characterized by the following four features:

> 1) the existence of a minority implies the existence of a dominant group enjoying higher social status and greater privileges; 2) minority status entails exclusion from full participation in the life of the society; 3) minorities are treated as peoples set apart, look upon themselves in that same light, and consequently develop attitudes and behavioral forms that exaggerate their distinctiveness and isolation; and 4) the minority concept is not 'statistical,' which means that a minority can outnumber the dominant group but still remain a minority in terms of its subordinate relationship to the latter (Gleason, 1991, p. 398).

As Gleason observes, perhaps the most important effect of Wirth's formulation was to cement the notion of *victimization* at the conceptual core of the term's meaning and usage (Gleason, 1991, p. 399).

The practical upshot of casting minorities as "victims" was, as Gleason shows, to provide recognized minority groups with a significant degree of moral-social power, as a consequence of which being classed as a "minority" became increasingly desirable. As Gleason explains it,

> [i]n this complex and confusing situation one thing was...unmistakably clear: in any contest between a minority group and the 'dominant group,' the moral advantage always lay with the former. Minorities, after all, were defined as victims, and their antagonists were presumed by the same definition to be guilty of harboring prejudice toward, if not hatred of, members of minority groups, and of practicing discrimination against them. This definition of the situation amounted to a tremendous form of moral and social power

> in the hands of minorities; eventually it made practically everyone want to be included in that category (Gleason, 1991, p. 400).

The irony of this, of course, was that "if being a victim of hatred and prejudice was intrinsic to minority status, it would seem almost perverse for minorities to wish to perpetuate their own existence" (Gleason, 1991, pp. 399-400).

Nevertheless, the minority concept continued to grow both in its scope of application and its appeal. As a result, however, the term also became increasingly imprecise as it was applied to "more and more elements in American society" (Gleason, 1991, p. 402). Indeed,

> [b]y the early 1970s, the minority concept was being stretched even further, and in less conventional directions, by a growing tendency among sociologists to merge the study of 'social deviance' with that of minorities. Thus anthologies began to appear dealing with 'the other minorities' – homosexuals, youth, the aged, the physically handicapped, the emotionally disturbed, the poor, drug users, alcoholics, convicts and ex-cons, and others on the margins of society (Gleason, 1991, p. 403).

One group in particular—African Americans—emerged as the paradigm case of a "minority" in the "postwar" period (Gleason, 1991, p. 403), a centrality that remains to this day.

The increased moral-social power afforded these newly-minted "minority" groups also resulted in their enjoying greater moral-political leverage—a fact that helps to explain why the status became so appealing. As Gleason puts it, on this new understanding, "[b]ecause minorities are by definition victims of unequal treatment, their complaints enjoy *prima facie* justification and their claims for redress gain an automatic moral legitimacy" (Gleason, 1991, p. 403). No wonder, then, that various groups increasingly *sought* the "minority" designation.

The "present ubiquity" and "unprecedented practical importance" of the term 'minority' has, on Gleason's account, also been fueled in large part in the American context by the nation's "historical theoretical commitment to equality as a fundamental value" (Gleason, 1991, p. 403). Indeed, as Gleason puts it, the emergence of African Americans as the paradigm example of the new conception of a "minority" group "would have been without effect—or at least its effect would have been greatly diminished—without" that prior historical commitment in the background

(Gleason, 1991, p. 404). That historical commitment, and the attempt to make "equality a meaningful reality in American society," has, in turn, featured largely in what Gleason identifies as the key development that has given the term "minority" such a central place in contemporary society—namely, the development of "affirmative action" policies. Affirmative action has, on Gleason's account, had a profound and perhaps unparalleled impact on the development and use of the 'minority' term (Gleason, 1991, p. 404)

One key impact of affirmative action policies has been to cause the term 'minority' to take on a "quasi-legal status" (Gleason, 1991, p. 404), on the basis of which some—but not all—"minority groups" are explicitly afforded certain legal protections or benefits. That is, under affirmative action policies minority status "applies only to certain 'designated,' or 'protected,' minorities, and not to all the groups that might hitherto have been thought of as minorities, or might still be so considered in the nonlegal sense" (Gleason, 1991, p. 404)—resulting, in effect, in what Gleason refers to as a "two-track system" that pits "designated minorities" against "unrecognized minorities." Under this system, "'designated minorities' are more favorably situated than... 'unrecognized minorities,' since the former are entitled to benefits denied to the latter" (Gleason, 1991, p. 413). The problem with this, however, is that because (as previously noted) the scope of the term 'minority' has in practice become increasingly "elastic and imprecise" (Gleason, 1991, p. 405), there now are "no clearly established, or explicitly agreed upon, criteria by which to distinguish designated minorities from the 'unrecognized' variety." As a consequence of this situation, "in which significant benefits are awarded on the basis of informal criteria which are subject to *ad hoc* modification" as the category of "minority" is either expanded or contracted, much controversy has been engendered over "over what constitutes 'minority' status, who ought to be included, and whose special claims are in peril of being submerged by promiscuous expansion of the category" (Gleason, 1991, p. 414).

This latter point suggests several additional problems that critics have raised concerning the contemporary concept of "minority." Some commentators have criticized minority-talk as being stigmatizing. Here, the ideas is that "to be labeled a minority stigmatizes people and robs them of self-esteem" (Gleason, 1991, p. 410). Moreover, there can be a practical difficulty

associated with potentially conflicting rights-claims *among* different minority groups (at the inter-group and intra-group levels) [Gleason, 1991, p. 411]. Finally, a more basic theoretical issue concerns the question of "whether group membership—defined on the basis of race, ethnicity, or anything of the sort—*should* entitle a person to benefits not available to any other citizen" (Gleason, 1991, p. 414). The question, in other words, is this: do rights attach to *groups* or to *individuals*? As Gleason explains the point, "the new understanding of minorities raises the fundamental question whether rights are to be understood as appertaining to *groups,* and to individuals in consequence of their belonging to those groups, or to *individuals* in their character as persons and citizens, with no regard to other forms of group membership" (Gleason, 1991, p. 414). The answers to these questions have generated intense controversy and dispute, and the questions themselves demonstrate clearly that the "minority" concept itself carries with it a significant "moral dimension" (Gleason, 1991, p. 419, n. 31, citing William Petersen).

B. *How* do groups make claims to minority status?

In an article titled "Making Minorities: Cultural Space, Stigma Transformation Frames, and the Categorical Status Claims of Deaf, Gay, and White Supremacist Activists in Late Twentieth Century America," Berbrier (2002) compares the attempts of activists from three different groups—the Deaf, gay, and white supremacist communities—to move their groups from a "stigmatized' to a "valued" status, by way of making both "contiguity" and "distance" claims in comparison to "minorities" and "deviant" groups, respectively. This involves claims of resemblance to established minority groups ("claims of contiguity") and claims of being different from "groups stigmatized as deviant" ("claims of distance"). The upshot of framing themselves in terms of minority status ("minority status framing") is that it "enables stigmatized groups to claim legitimacy without changing" (Berbrier, 2002, quotes from abstract).

As Berbrier explains in his paper, recent sociological studies of "identity" have moved away from a focus on "individual and essential identities" toward an "emphasis on the construction and legitimation of collective identities" (Berbrier, 2002, pp. 553, citing Calhoun, 1994 and Cerulo, 1997). In this context, Berbrier's particular interest is in the question of "how groups make claims to the status of 'minority' and in how those claims are interrelated" (Berbrier,

2002, pp. 554). To this end, he examines the attempts of three disparate groups—the deaf, gays, and white supremacists—to overcome what they perceive to be a "stigmatized" status by making claims of similarity with established minority groups ("claims of contiguity") and of dissimilarity to groups stigmatized as "deviant" ("claims of distance"). In developing his analysis, Berbrier employs a "cartographic approach," which relies upon the metaphor of maps and mapmaking; as Berbrier explains the idea, "we can clarify our thinking about cultural categories by interpreting them as things that are mapped by social actors—as contiguous to or distant from each other, as central or peripheral locations, or as more or less desirable places to be" (Berbier, 2002, p. 554). Stigmatized groups attempt to relocate themselves from one cultural "space" ("deviant") into another ("minority") by means of a process of "stigma transformation" (Berbrier, 2002, p. 554). Regarding this process, Berbrier's analysis advances three central theses:

> I find (i) that 'minority' spaces are reliably constructed as desirable social locations, (ii) that successful frame transformation (moving from deviant to minority space) implies achieving normality without changing behavior, and (iii) that minority cultural spaces are imagined these days with African Americans at their center: In late twentieth century America blacks are the major point of reference for those seeking to enter 'minority' cultural space (Berbrier, 2002, p. 554).

Minority spaces have come to be considered "desirable" in large part because of the association—flowing from Wirth's (1945) seminal formulation—of the term 'minority' with "victimization" (Berbier, 2002, pp. 554-555). This association has afforded to minority status a great deal of "moral power": "With the recognition of minority status comes greater potential for the recognition of grievances as legitimate" (Berbrier, 2002, pp. 554-555). That moral power has also tended to give rise to "a form of political organization: "If minority status meant the cultural legitimation of a victim status, official minority status resulted in grievances being addressed through the apparatus of the state (cf. Olzak and Nagel, 1986), often via a 'civil rights master frame' (Snow and Benford, 1992:148)" (Berbier, 2002, p. 556). Not surprisingly, this rendered "minority status" as "increasingly attractive" during the twentieth century; moreover, groups

previously designated as "deviant" increasingly sought to change that status to one of "minority" (Berbrier, 2002, p. 556).

On Wirth's formulation of the term, the central criterion for qualifying as a "minority" was a subjective perception of being the recipient of "differential and unequal treatment" (Berbrier, 2002, p. 556). For Wirth, the paradigm cases of "minorities" were "ethnic racial, national and religious" groups (Wirth, 1945, p. 350, quoted in Berbrier, 2002, p. 556); however, as Berbrier notes, that definition "was sufficiently broad that others could and indeed would also use it to lay claim to the territory" (Berbier, 2002, p. 556). This soon came to include many groups, including those advocating on behalf of the disabled.

Returning to Berbrier's cartographic metaphor, we can say that "there exist on many people's cultural maps deviant cultural spaces where stigmatized individuals or groups may be assigned" (Berbier, 2002, p. 557). Berbier examines the rhetoric of three groups—"the Deaf, gays, and White supremacists"—all of whom "present themselves as having been labeled, stigmatized, or otherwise assigned status in a deviant cultural space" (Berbier, 2002, p. 557). To counter such perceived stigmatization, these groups engage in a strategy of claiming "nondeviance" (Berbrier, 2002, p. 557). This strategy—which Phuhl and Henry (1993) have termed "stigma transformation," drawing on Goffman's classic work on the management of stigma, or "spoiled identity" (Goffman, 1963)—focuses not on changing the *individual* person from being "deviant" to "non-deviant," but rather "involves the use of moral entrepreneurship strategies to change the meaning of the label (Becker, 1963)—to move it from one space to another on the cultural map" (Berbrier, 2002, p. 557). "Minority" status—which on this approach is conceived as a distinct, non-overlapping, mutually exclusive category in contrast to that of "deviant"—is viewed as a comparatively more desirable place to be on the cultural "map," thereby justifying the attempt to relocate the "marginalized" group from one space to the other (Berbrier, 2002, p. 557). This process is a dynamic one in which the boundaries of various "spaces" on the cultural "map" are "negotiated by those who wish to enter particular spaces in particular locations on their cultural maps," inclusion or exclusion from which has significant "material and/or symbolic consequences"

at both the individual and group levels—consequences that "are, or at least are perceived to be, greatly divergent" (Berbrier, 2002, pp. 557-558, 560).

As an example of this process, Berbier presents the case of the Deaf Culture Movement. At the heart of this movement's ideological strategy, on Berbrier's account, is an attempt to move the deaf community from a status of "deviant" by virtue of being unable to hear, to a status of a linguistic "minority" in virtue of the fact that deaf persons use a different language (i.e., sign language) [Berbrier, 2002, p. 262]. Moreover, a key causal claim is made—namely, that the "main cause" of the problems experienced by deaf persons is primarily "the dominant Hearing society, at whose hands activists present Deaf people as victims of both ignorance and discrimination" (Berbrier, 2002, p. 563).

As Berbrier explains, "[i]n staking their claims, advocates of Deaf Culture... present deafness not as a disability but rather as a difference that qualifies the deaf person for membership in a linguistic minority group based on American Sign Language" (Berbier, 2002, pp. 562-563). Indeed, the "disability" label is typically rejected outright; one advocate, for example, puts it this way:

> I cannot agree that Deaf people belong in the disabled group. To me, what lies behind this view is the assumption that there is a defect—a brokenness. But the meaning of Deaf is **not** "cannot hear." In fact, Deaf people are a distinct minority group with a separate language and culture that has often been overlooked and/or oppressed by the hearing majority (Bienvenu, 1989, p. 1, boldface in original, quoted in Berbrier, 2002, pp. 562-563)

The underlying idea here is a distinction between conceptualizing deafness as a *pathological state,* versus adopting a

> *cultural view of Deaf people* that not only emphasizes that they are neither diseased nor disabled, but goes further in explicitly portraying a contrasting conceptual option: the Deaf as a minority group with a distinct history, unique values, a heritage, a culture, and especially a language, ASL (Berbrier, 2002, pp. 562-563).

Deaf Culturalists argue for the adoption of the latter view over against the former, and thus lay claim to "minority" status in the cultural landscape.

As Berbrier points out, this strategy involves two distinct types of claims, both of which are crucial to the larger argument in which Deaf Culturalists are engaged. First, there is an explicit *dissociation* from other groups labeled "disabled'; second, there is an explicit *association* with other minority groups. Each of these moves has important conceptual and practical ramifications. On the one hand, by dissociating from "disabled" groups,

> Deaf Culturalists reject traditional associations of deafness with health and medical issues.... The distance claim extricates the group from a disease status by again forcefully claiming spatial contiguity to minority space. Here, ... the contiguity claim is one of consistency with putative characteristics of minorities: these people have their own 'language' and 'culture' and are 'oppressed' by a dominant majority group fixated on denying them their 'civil rights. The discourse is repeatedly evocative both of Wirth's seminal definition of 'minority' in terms of criteria emphasizing discrimination, as well as the rights rhetoric of the Civil Rights Movement (Berbrier, 2002, pp. 563-564).

On the other hand, by explicitly *associating* with minorities,

> Deaf Culturalists regularly deny the need for a cure for deafness by comparing this to the curing of 'minorities.' The attitude of curing Deaf people who are socially and culturally Deaf—and comfortable in that status—and making them into another kind of cultural being (Hearing) is presented as having eugenicist overtones with, according to more than one DC advocate, 'genocidal' intentions (Alden, 1997; Montgomery, 1993; Treesberg, 1990)" [Berbrier, 2002, p. 564].

As Berbrier notes, the comparisons to African American is quite intentional and "represent, next to American Sign Language, the rhetorically most elaborated aspect of DC claims" (Berbrier, 2002, p. 565, citing Rittenhouse and Dokes, 1992). Indeed, "[t]here is a clear and conscious effort to follow in the footsteps of the Civil Rights Movement of the 1960s, a borrowing of themes known as 'frame diffusion' (Berbrier, 2002, p. 565, citing Benford and Snow, 2000).

In seeking to effect this stigma transformation, involving a relocation in cultural space from "deviant" to "minority," the Deaf Culture Movement seeks to realize a number of material and nonmaterial gains. Among these are the "nonmaterial benefits of increased respect, improved self-esteem, and decreased pity, as well as the material benefits sometimes conferred upon recognized 'minorities' by and through educational and other state institutions" (Berbrier, 2002, p. 566).

Berbrier draws analogies between the Deaf Culture Movement and the attempt on the part of gays to gain "minority" status over against the "deviant" label. Both cases, he says, "illustrate well the multidimensionality of deviance," by which he means "the tendency in modern societies to medicalize, criminalize, and moralize about difference" (Berbrier, 2002, p. 566). This "multidimensionality," however, occurs "with differing degrees of salience" in each case:

> Like deafness, homosexuality has been considered a disorder meriting treatments and cures and, as we shall see, minority status is again presented as incompatible with medicalization. On the other hand, while the implication of lesser moral status has at times been part of the oppression of the Deaf, both the putative sinfulness as well as the criminalization of homosexuality have played much more significant roles in the experiences of lesbians and gays (Berbrier, 2002, p. 566).

What is abundantly clear in both cases is that inclusion in "minority cultural space" has come to carry with it tremendous political value. In part this can be traced to a change in the "political opportunity structure" that came about during the second half of the twentieth century, according to which recognized minority groups were increasingly granted tangible benefits (protections, resources, etc.) by the state. In the context of such a political opportunity structure, it is natural for groups to seek out minority status: "when state resources and favors come to be apportioned on the basis of minority status, then instrumentally oriented mobilization around that status will result—in order to rationally exploit the extant political opportunity structure" (Berbrier, 2002, citing Eisinger, 1973).

The pursuit of minority status by advocates for the Deaf Culture Movement and the gay community also occurred in the context of a particular "cultural opportunity structure" (Berbier, 2002, pp. 572-573). As Berbrier explains,

> in late twentieth century America there developed a different *cultural opportunity structure* (Frank and McEneaney, 1999; Snow and Benford, 2000) with respect to minority status. In the past, minority status was shunned, considered an aberration that over time would and should disappear to the forces of assimilation. But the social movements of the 1960s, the legislation they engendered, and the discursive forms they cultivated, changed that. They legitimated cultural pluralism, and its offshoot ideology of multiculturalism (Jankowski, 1997), and conferred 'cultural resonance' upon the notion that difference and diversity ought be celebrated rather than controlled, monitored, or changed. Goffman's 'abominations of the tribe' (Goffman, 1963) became less abominations, and indeed, less stigmata; rather such 'tribal' affiliations may now better fit Goffman's other notion of identity norms (Goffman, 1963): people are expected to hold a minority identity of some sort (Alba, 1990) and a minority status becomes the norm—it means normality and its recognition confers just that. This contrasts strongly to the historical situation facing Deaf people and gays where in both cases 'normality' could be attained only via assimilation and conformity to the dominant culture (gays were to become heterosexual and the deaf to become, if not hearing, then more like hearing people—speaking English, integrating in the hearing world, having cochlear implant surgery). But the cultural opportunity structure of the late twentieth century offered normality within the context of difference. The categorical status of 'minority' thus provided a powerful new cultural tool through which stigmatized groups could become nondeviant without having to change. [Berbier, 2002, pp. 572-573]

In the context of this "cultural opportunity structure," then, groups seeking minority status (instead of the "deviant" category) seek not only to *express* what they take to be their "identity," but also the *normalization* of that identity as well (Berbier, 2002, pp. 572-573). Importantly, too, limited "cultural opportunity structures" promote "frame diffusion"—that is, the borrowing of themes from

one movement for cultural acceptance/legitimacy for use in another movement (Berbrier, 2002, pp. 581-582). This helps to explain why the Deaf Culture movement in particular, and the "disability culture" and "disability rights" movements more generally, have been so consistently and explicitly patterned on the Civil Rights movement of the 1960s and other similar movements. These movements thus employ what has been termed "masterframe transformation processes"—that is, frames used by several movements that, among other things, function to "move groups and transform stigmata" (Berbier, 2002, pp. 581-582).

As with all such movements, however, there is always a cost associated with seeking minority status—what has been termed "the dilemma of identity movements" (Berbrier, 2002, pp. 582-583, quoting Gamson, 1995). As Berbier explains it (drawing on Gamson's [1995] formulation), this dilemma consists in the reality that

> while claimants for identity movements assert essential, fixed, and natural identities, it is these very kinds of 'fixed identity categories [that] are both the basis for oppression and ... for political power" (Gamson, 1995:391). More specifically, Gamson points out that at this particular junction in history, the political opportunity structure requires 'clear categories of collective identity ... for successful resistance strategies' (Gamson, 1995:391), and it is only through clear minority status that minority rights can be conferred. However, in the long term, deconstructionists—such as queer activists—maintain that this kind of politicking merely reinforces the basis of oppression, understood as the binary categorical distinction between normality and deviance. Gamson (1995) describes how queer theorists have thereby developed a case for destabilizing the binary distinction between hetero- and homosexual identities, arguing against the minority strategy and proposing the obliteration of distinctions among sexual-orientation categories. Fixed identity categories, in this view, are part of the arsenal of the social control of sexuality and from this point of view 'disrupting those categories [and] refusing rather than embracing ethnic minority status, is the key to liberation' (Gamson, 1995:391). [Berbier, 2002, pp. 582-583]

Whether and to what extent this "dilemma" applies in the case of the Deaf Culture Movement is, Berbrier points out, not entirely clear. This is because

> [t]he source of oppression in this case has been hearing people's assumption that physiological deafness was not a serious obstacle to becoming culturally hearing. That is, the problems asserted by Deaf activists have been less a result of hearing people assuming the binary and fixed difference of Deaf versus Hearing, but of the opposite: hearing people ignoring, denying, and minimizing that difference, and assuming that Deaf people should learn spoken language, and, with the proper training, could learn it as well as hearing people. The basis of oppression for Deaf people then, is not the distinction but its denial.

All the same, there can be other, shorter-term "hidden costs" associated with asserting minority status. As Berbrier explains,

> Queer activists and others argue that this includes "the repression of differences among lesbians and gay men, a narrow focus on legitimating same-sex preference, [and] the isolation of the gay movement from other movements" (Seidman et al., 1999:10). Similarly for the Deaf, asserting minority status is said to maintain a narrow parochial focus (Stewart, 1992), pit them against hard-of-hearing people and those who become deaf late in life (Woodcock, 1992), and may also isolate them from other movements, such as those for the rights of the disabled (cf. Berbrier 1998b). [Berbier, 2002, p. 583]

Criticisms of the "minority group" strategy have also been advanced by certain "liberal assimilationist and integrationist critics of multiculturalism" (Berbrier, 2002, pp. 582-583, citing Downey, 1999). These critics assert that

> the strength of the American nation lies in its unity rather than its diversity, and on a model of progress through consensus rather than conflict. While generally recognizing the short-term political efficacy of the minority strategy, they argue that by normalizing and institutionalizing minority status we risk institutionalizing a perpetual "politics of difference," resulting in "the balkanization of America" (Schlesinger, 1992). [Berbrier, 2002, pp. 583-584]

Finally, Berbrier notes, the goal of the "minority group" strategy is itself a moving target. That is to say,

> [p]eople try not only to move themselves or their ideas and institutions from what they perceive as less desirable to more desirable neighborhoods, but these spaces themselves are moving targets, variably and episodically constructed in manners that suit these and other claimants' perceived interests. While they become somewhat sedimented over numerous episodes (which ultimately make up the contexts and systems, which provide situational and historical constraints), deviant and minority spaces are still and always unstable, and ultimately changing with the advent of new and different sets of episodes and events. Thus, while these days stigma transformation can be attempted by claiming status in a minority space in which African Americans are centrally located, and while these reflect fundamental historical shifts in the cultural meanings of things like deviance, minority status, as well as the status of African Americans and other groups, these are but meanings that are sure to change. [Berbrier, 2002, p. 584]

III. DISABILITY AND STIMGA

Claims to recognized minority status often are made, at least in part, in terms of an appeal to having been *stigmatized.* And, as we have seen throughout this work, this claim is frequently advanced in the context of the various debates over disability. This begs the following two questions: (1) what exactly is *meant* by the term "stigma," and (2) what does it mean to say that the *disabled* are, or have been, stigmatized? This part of Chapter 6 explores these issues further.

If the project being undertaken in this work is to be successful, it will be necessary to engage in a careful consideration of the concerns of many disability rights activists with the reality and effects of stigma and stigmatization of the disabled. In particular, we shall consider the oft-advanced claim that the medical model has the effect of stigmatizing (or marginalizing) those with disabilities (see, e.g., Oliver, 1990; Silvers, 1998). This is frequently taken to be a decisive

objection to the medical model, and so is important to this project's contention that the medical and social models *are* in fact compatible with one another (in certain respects), but must in turn be incorporated into a broader, "biopsychosocial" understanding of disability.

This section's primary concern is thus with a consideration of the notion of "stigma" in its particular application in the context of the literature on the nature of disability. This will involve, *inter alia*, interaction with Goffman's (1986/1963) account of stigma (the *locus classicus* for contemporary discussions of the concept) and more recent accounts, with a view toward answering the question, "what is stigma?" From there, we shall consider several examples of what might be termed "disability stigma." For purposes of this exploration, we shall assume that such a notion can be made out coherently, and that such stigmatizing of the disabled does occur, on at least some occasions. Operating on that assumption, we shall focus our attention squarely on the relationship between disability and stigma, addressing, first, the question of what might be the *cause* (or causes) of disability stigma, followed, second, by a consideration of whether or not the so-called medical model of disability *itself* stigmatizes the disabled.

With regard to the former question, a number of candidate "causes" have been offered in the literature—among them, (a) displaced fear/abjection, and (b) a cognitive mistake stemming from a failure to identify with the disabled (Silvers, 1998). With respect to each of these candidate causes, we will engage in a brief critical analysis of the arguments offered in support of them. In short, the thesis of this section with respect to these matters is two-fold: (1) the causes of disability stigma are likely multiple and varied; and (2) the medical model of disability does not *in itself* stigmatize (or cause stigmatization to occur)—rather, disability stigma arises as a function of how individuals (and/or society) *respond to* the findings/pronouncements of the medical model of disability. In other words, there is no necessary connection between the "medical model of disability" and "disability stigma."

A. What is Stigma?

We begin this section with a brief overview of some typical understandings of the term "stigma," as found in contemporary literature on the subject. The primary methodology employed in this and the following section (on "disability stigma") will be that of a literature review; the

objective will be to provide representative samples rather than an exhaustive survey. The overriding aim for now is not to provide a detailed analysis of these accounts of stigma, nor to develop a critique of their respective merits and demerits, but rather to map out, in general terms, a geography of what writers and thinkers on the topic commonly have in mind when they speak of "stigma," "stigmatization," "disability stigma," and the like. This background should help us better to grasp the issues at stake when focusing our attention more narrowly on questions related to stigmatization of the disabled.

1. General accounts of stigma

Erving Goffman's (1986/1963) sociological account of stigma has become the *locus classicus* for contemporary discussions of the concept,[1] and thus will serve as a useful starting point for the present discussion as well. For Goffman, the essence of stigmatization is a process of dehumanization that leads to discrimination against the object of such dehumanization, which in turn results in a constriction of that individual's ability to pursue various life plans (which constriction would not occur but for the aforementioned dehumanization and discrimination). As Goffman puts it,

> [b]y definition..., we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class (Goffman, 1997, p. 205).

On Goffman's account, then, the stigmatized individual is "disqualified from full social acceptance" (quoted in Veatch, 1986, p. 190).

Goffman identifies three distinct species of stigma: (1) that which attaches to "physical deformities," (2) that which is taken to indicate (in Goffman's terms) the presence of "'blemishes of individual character' (such as weak will, dishonesty, alcoholism, etc.)," and (3) that which is

[1] Goffman's *Stigma: Notes on the Management of Spoiled Identity* is, according to Robert Veatch, "the classical statement of the sociology of stigma" (Veatch, 1986, p. 190).

related to "tribal stigma of race, nation, or religion transmitted through lineages" (Veatch, 1986, p. 190, citing Goffman).

Barnes and Mercer (2003) provide further elucidation of the main features of Goffman's account of stigma. Three points stand out in particular. First, stigma is associated with what Goffman terms a "spoiled identity." This encompasses, among other stigmatizing conditions, "'abominations of the body', with illustrations of those described as 'blind', 'deaf', 'crippled', 'deformed', 'disfigured', 'mentally ill' and 'stutterers'" (Barnes & Mercer, 2003, p. 6). Those who find themselves either actually or potentially stigmatized must learn to

> manage their 'spoiled identity' in everyday social interactions... Encounters between 'normals' and 'stigmatized' people are characterized by immediate and often acute tensions for the visibly 'discredited', while for the 'discreditable' whose stigma is not immediately apparent the dilemma is whether or not to display their 'abnormality' (Barnes & Mercer, 2003, pp. 6-7).

Moreover, stigmatized individuals—particularly those with visible stigmatizing conditions, such as certain physical impairments or defects—must be concerned with the potential for that stigma to "spread" to those around them, such as family members. Goffman refers to this latter phenomenon as a "courtesy stigma."[2]

Further, as Robert Veatch explains, "stigma" is an inherently evaluative notion. More precisely, it necessarily involves a *negative* value judgment: "[i]t is impossible to have a good stigmatizing condition."[3] At its root, "[t]he entire theory of stigmatization rests on the purported fact that social groups necessarily create we/they dichotomies." If this assumption is correct,[4] Veatch argues, then it has an important implication for those who carry "invisible" stigmas—that is, stigmatizing conditions that are "hideable," thus enabling the potentially stigmatizable individual to "pass for normal" (Veatch, 1986, pp. 194-195). That implication is that "[s]ome [social/public]

---

[2] According to Barnes and Mercer, "[t]he stigma label is further characterized by its potential to 'spread'. At the individual level, physical impairment is sometimes taken as an indication of a generalized incapacity—as typified by the 'Does he or she take sugar?' syndrome. In addition, negative attitudes and behaviours may be extended to other family members as a 'courtesy stigma' (Goffman 1963)" [Barnes & Mercer, 2003, p. 7].

[3] According to Veatch, "Handicap is a similar term. It is impossible to refer to a 'good' handicap (except in a relative or indirect way). To label a condition as a handicap is to say simultaneously that it is a condition we would rather not have" (Veatch, 1986, p. 191).

[4] Veatch ultimately rejects the necessity of creating a "we/they" dichotomy, thus opening an avenue for an egalitarian solution to the problem of stigma—namely, by (in Veatch's terms) "destroying the we/they dichotomy." We will briefly return to this proposed solution later in this section.

policies may increase the visibility of the we/they dichotomy and thus make the burdens of stigma worse."[5]

In an effort to harmonize more recent accounts of stigma with classic accounts such as Goffman's, Lerita M. Coleman (1997) develops a more expansive account of the concept, one which delineates three principal components of the phenomenon of stigma: an "affective," "cognitive," and "behavioral" component, respectively. On Davis' account, "fear" is "stigma's primary affective component; stereotyping, its primary cognitive component; and social control, its primary behavioral component" (Coleman, 1997, p. 227). Moreover, on Coleman's view, stigma is "not primarily a property of individuals as many have conceptualized it to be," but rather

> a humanly constructed perception, constantly in flux and legitimizing our negative responses to human differences.... To further clarify the definition of stigma, one must differentiate between an 'undesired differentness' that is likely to lead to feelings of stigmatization and actual forms of stigmatization.... *stigmatization occurs only when the social control component is imposed, or when the undesired differentness leads to some restriction in physical and social mobility and access to opportunities that allow an individual to develop his or her potential. This definition combines the original meaning of stigma with more contemporary notions and uses* (Coleman, 1997, p. 227, italics in original).

To summarize, "stigma" as employed in the contemporary literature typically encompasses (1) some connection between dehumanization of a stigmatized object, on the one hand, and discrimination against and a reduction in range of opportunities for the object of stigmatization, on the other; (2) the notion that the identity of the stigmatized object has in some sense been "spoiled"; (3) acknowledgement that some individuals are able to "hide" their potentially stigmatizing conditions, or "pass for normal," thus creating distinctions between the (actually) "discredited" and the (potentially) "discreditable," and between "visible" and "invisible" stigmas; (4) a conviction that the driving force behind stigmatization is a tendency to create

[5] That is, "[t]he fact that some can 'pass for normal' when their stigmatizing condition is hideable is important when a community decides whether to adopt public policy (such as classifying and compensating) that will increase visibility. It has been observed by labeling theorists that the development of classification schemes and even the mere naming of a particular condition can increase its visibility and therefore make it more difficult for the stigmatizable person to pass as normal" (Veatch, 1986, p. 194).

"we/they" dichotomies, where the dominant "we" view the minority "they" as inferior and therefore proceed to stigmatize them; and (5) some combination of affective, cognitive, and behavioral components (such as fear, stereotyping, and social control).

2. Disability stigma

Disability rights advocates frequently claim that a similar kind of stigma, what we might term "disability stigma," attaches to those who bear some forms of disability. Anita Silvers, for example, references Jenny Morris' identification of three examples of disability stigma exemplified in public policy:

> [Jenny] Morris came to recognize, and to be threatened by, the bias that accords the lives of people with disabilities so little value. In an essay called 'Tyrannies of Perfection,' she cites three examples of public policies that evidence the low regard in which disabled people's lives are held. These are (1) American court rulings that it is entirely rational for a person with a serious physical impairment to choose to die, (2) British legislation excepting pregnancies diagnosed as likely to result in children with disabilities from a prohibition against terminating past twenty-four weeks, and (3) the 1939 German decree authorizing physicians to accord a mercy death to impaired persons who could not be cured. About the last example, Morris reminds us, from 1939 to 1941 two hundred thousand physically and mentally impaired children and adults were judged to have 'lives unworthy of life' and were killed 'out of pity for the victim and out of a desire to free the family and loved ones from a lifetime of needless sacrifice,' to quote one of the physicians who signed the death warrants (Silvers, 1998, p. 41).

a. Prenatal Testing and the Abortion Presumption

Arguably, this "low regard" for the lives of disabled persons is evidenced most dramatically in the increasingly-routine practice of prenatal testing for disability, and the "abortion presumption"—i.e., the assumption that if a fetus is found to be "defective," it will or at least should be aborted in order to "prevent" disability—that nearly always accompanies such testing. As Leon Kass expresses the underlying idea,

> we know that persons afflicted with certain diseases will never be capable of living the full life of a human being...so a child or fetus with... Down's (sic) syndrome, will never be truly human... There is no reason to keep them alive. This standard, I would suggest, is the one which most physicians and genetic counselors appeal to in their hearts, no matter what they say or do... Why else would they have developed genetic counseling? (Cited in Silvers, 1998, p. 42)

Given the apparent prevalence of this "standard," disability advocates are understandably concerned about its implications for the disability community. As Alan Fleischman puts it, "I'm concerned that as more abnormal children are prevented through abortion and testing, we'll be less tolerant of abnormality. We'll blame families if they knew there would be an abnormal child but chose not to abort" (cited in Silvers, 1998, p. 43). In sum, as Silvers concludes, "[t]oday, the conviction that society repudiates the lives of people who are disabled is widespread and widely discussed" (Silvers, 1998, p. 43).

What explains this "abortion presumption"? Adrienne Asch and David Wasserman (2005) argue that in at least some cases, prenatal testing for disability, when accompanied by a decision to abort on the basis of a finding of disability, commits the "sin of synecdoche." When using the term "synecdoche," Asch and Wasserman have in mind "not the literary device, in which the part stands for the whole, but the characteristic response to a stigmatized trait in which the part obscures or effaces the whole" (Asch & Wassserman, 2005, p. 173). The "sin of synecdoche," in turn, involves "the uncritical reliance on a stigma-driven inference from a single feature to a whole future life" (Asch & Wasserman, 2005, 181). In this context, the "sin of synecdoche" is

> to allow a single known characteristic of the future child so to overwhelm and negate all other hoped-for attributes that the prospective parents no longer desire the coming-into-being of that child. The sway exercised by that single characteristic is not accidental or idiosyncratic—it is the sadly predictable effect of stigma 'spoiling the identity' (Goffman, 1963) of the future child in the most radical possible way, by precluding him from ever forming an identity in which the impairment might play only a slight or negligible role. In responding to that characteristic as they do, parents who test and abort for an impairment

ratify and perpetuate its stigmatization, however unwittingly or reluctantly. Synecdoche is thus a sin about which other people—people stigmatized by possession of the same impairment—have special standing to complain (Asch & Wasserman, 2005, p. 182).

b. Disability: intrinsically or instrumentally bad?

Underlying the general discussion of disability as a stigmatizing condition, and the debate over the appropriateness of prenatal genetic testing when combined with an "abortion presumption," is the closely related debate concerning whether having a disability is *intrinsically* or only *instrumentally* bad. Many disability rights advocates question the intrinsic badness of disability, and see in the claim that disability *is* intrinsically bad a fundamental root of stigmatization of the disabled. Thus, according to Anita Silvers, "[t]he discourse of the wider culture lays a special burden of proving the value of their presence and participation on people with disabilities" (Silvers, 1998, pp. 86-87). There is, she argues, "a grave inequity in the heaviness of the burden of proof imposed on those who approach being disabled nonjudgmentally compared with the light burden of proof placed on those who think that being deaf or blind or crippled is intrinsically bad" (Silvers, 1998, p. 88).

As we have seen already, this "grave inequity" in the "burden of proof" typically yields an "abortion presumption" when the results of prenatal genetic testing are found to indicate the presence of or predisposition to serious disease or disability. In light of this presumption, Anita Silvers argues for the superiority of her preferred "social model of disability" over against the "medical model" of disability" (a topic to which we shall return later in this section):

> What we have seen so far is that the suffering we would avoid by preventing children with disabilities from coming into the world is not the consequence of being impaired but rather reflects the anguish of those who cannot bear to bear culturally repudiated offspring. Here, the social model of disability usefully reminds us that it is not the individual but the environment that is defective. The more a society oppresses certain classes of people, the more pressing may be our moral obligation to defend the procreation of the class's members against its enemies. We magnify oppression if we permit flawed social arrangements to cause us to be overcome with despair and to

> depreciate the lives of people just because they suffer from being oppressed. Consequently, in contrast to the medical model of disability, the social model directs us to address the suffering of people with disabilities by eliminating or reforming the external circumstances that contribute to it rather than by eliminating or revising the people themselves (Silvers, 1998, p. 94).[6]

To be sure, some of Silvers' contentions here are potentially disputable. For example, one might question her implicit claim that the so-called "medical model of disability" is incapable of doing just what she proposes here—namely, addressing *suffering* without attempting to eliminate the *sufferer*. To put the point differently, why think that the medical model *cannot* effectively distinguish between "eliminating and "revising"? For that matter, why think that the medical model *does* warrant "eliminating" the sufferer in the first place? At the very least, these claims require further support. All this having been said, the key point for present purposes is simply to adduce, by way of citing a prominent disability rights advocate (one who is herself a member of the disability community), additional evidence that many disabled persons perceive themselves to be stigmatized by their disabled status. As the above citation indicates, many disabled persons feel their lives are "culturally repudiated," that they are "oppressed" by a society that insists that *they* are "defective" individuals who must in some way be "repaired" or "revised."

In sum, cultural analysis appears to reveal, at the very least, disparate trends with respect to societal attitudes toward the disabled. On the one hand, legislation such as the 1988 Air Carriers Access Act—which "protects people with disabilities from the injurious consequences of being stigmatized as burdensomely or dangerously incompetent travelers just because they are disabled" (Silvers, 1998, p. 125)—and the landmark Americans with Disabilities Act (1990) increasingly open the windows of opportunity for persons with disabilities to participate in the broader culture. Indeed, the very passage of these legislative acts (and others like it) indicate, at minimum, the *perception* that the disabled constitute a (perhaps increasingly) stigmatized class,

---

[6] Ruth Faden has argued along similar lines in the context of a discussion of prenatal HIV screening: Eliminating an incident of disease or disability by 'preventing' the person who would have the disease or disability from being born is not an instance of prevention—not in the sense in which it is ordinarily meant and not as the term ought to be used.... It suggests that the lives of some persons with a disability or illness are not worth living, that such persons are to be understood only as social or economic drains and never as sources of either independent value or enrichment for the lives of others (Faden, 1994, p. 92, cited in Juengst, 2004, p. 259, n. 4).

and the need to correct the effects of such stigma. On the other hand, the increasing reliance upon prenatal testing for disability, and its accompanying "abortion presumption," arguably indicates a growing unwillingness to permit "defective" individuals to come into or continue in existence. As Angier puts it, "the dominant culture appears to be moving in two contradictory directions: more accommodation of disabilities in adults, but less tolerant of imperfections in children."[7]

c. Disability stigma and the biomedical ethics literature

In "Disability Rights: Do We Really Mean It?" (2009), Ron Amundson argues that the attitudes expressed by many in the academic community towards persons with disabilities are often inappropriate, and that this can be seen particularly in the continued failure of many mainstream academics to grant to the disability rights movement the same degree of legitimacy that is attributed to other civil rights movements. In support of this claim, Amundson points to certain arguments contained in *From Chance to Choice* (Buchanan, Brock, Daniels, & Wikler, 2000), in an effort to show that many academics openly express demeaning attitudes towards those with disabilities—attitudes which would be deemed unacceptable were they to be expressed towards other disadvantaged groups. For example, the authors of *From Chance to Choice* imply that integrating persons with disabilities into society is in many cases "unduly burdensome to others" (Buchanan, Brock, Wikler, & Daniels, 2000, p. 320) and that the dominant group (in this case, the non-disabled population) has a morally legitimate interest in maintaining segregationist policies (the "maximizing interest"). Amundson argues that such comments would be decried if they were made in regard to racial minorities and women. However, in the case of those with disabilities, such comments are accepted without question.[8]

Central to Amundson's argument is the claim that justice involves more than the distribution of goods and services. Treating persons justly also entails showing them the respect that they deserve, and one way to show such respect is by displaying the appropriate attitudes

---

[7] Cited in Silvers, 1998, p. 118, n. 205. Similarly, bioethicist Daniel Brock has raised concern about the possibility that "as we come to understand genetic structures accurately enough to identity the potentially anomalous functioning consequent on every species' member's inheritance, some members of the species will find themselves devalued by their own futures" (cited in Silvers, 1998, p. 116).

[8] This paragraph is a modified version of material that originally appeared in the introduction to Ralston & Ho (2009, p. 11).

towards persons.[9] If it is true that persons who share the same morally relevant properties should be treated the same, and if it is also true that the disabled do not differ from the non-disabled in their morally relevant properties, then it follows that it is necessary for the non-disabled to work to alter their discriminatory attitudes towards persons with disabilities and to acknowledge that the disabled are no different (in any morally relevant way) than any other disadvantaged group.[10]

The central thesis of Amundson's (2009) essay is that "the disability rights (DR) movement has a much lower level of acceptance than other civil rights movements, especially within the academy." In particular, "[b]asic DR principles are rejected not only in practice but also in discourse," such that "discourse that defends the justice of socially inflicted disadvantage to people with impairments is not only accepted within the academy—it is virtually the norm" (2009, p. 169).

Amundson launches his discussion of these claims by first setting forth a number of "semantic stipulations" (p. 170). The first stipulation is a distinction between "biomedical conditions," on the one hand, and "the disadvantages that might be associated with them," on the other (p. 170). The significance of this distinction, Amundson says, is that it focuses our attention "on the contingent nature of the disadvantages that often accompany biomedical conditions" (p. 170). With this distinction in mind, one can then go on to distinguish further between (a) different kinds of biomedical conditions, on the one hand, and (b) different kinds of "disadvantages" that might be associated with various biomedical conditions. With respect to the former, we are interested in a specific category of biomedical conditions—namely, those that are properly called "impairments." Amundson defines the term 'impairment' as "a biomedical condition that is presumed to be subtypical of the human race, without any assumptions about the disadvantages that might accrue to individuals who possess impairments" (p. 170).[11] "Disadvantages," in turn, are divided by Amundson into two distinct categories: "those that are socially mediated (on the one hand), and those that are intrinsic to an impairment itself (on the other)" (p. 170). He specifies

---

[9] Rebecca Stangl (2010) discusses this in her article entitled "Selective Terminations and Respect for the Disabled."

[10] This paragraph is a modified version of material that originally appeared in the introduction to Ralston & Ho (2009, pp. 11-12).

[11] That is, a "neutral" conception of 'impairment.' In her (2003), Silvers argues in similar fashion for both the possibility and desirability of constructing a neutral conception of the term 'disability.'

this further by way of the aforementioned distinction between "conditional disadvantages of impairment" (CDI), on the one hand, and "unconditional disadvantages of impairment" (UDI), on the other (see discussion, earlier in this chapter, for Amundson's formal definitions of these terms, which are defined identically in his 2007 and 2009 essays). The dividing line between these two categories is, Amundson admits, partly subjective and inevitably "politically contentious." So, for example, a disadvantage that one group (say, critics of the DR movement) consider to be "unconditional," the opposing group (say, DR advocates) might take to be "conditional." But this, Amundson points out, "happens in all civil rights movements" and thus ought not to be taken as grounds for rejecting the CDI/UDI distinction (p. 170).

Groups that are "socially disadvantaged" often tend to be the objects of stigmatization (Amundson has Goffman's [1963] sense of "stigmatization" in mind here). Amundson believes this is true of people with impairments, and he locates the source of this stigmatization in certain assumptions that are made about the disadvantages associated with impairments. This stigma, in turn, Amundson takes to be the root cause of "the continued failure of so many mainstream academics to come to terms with the DR movement, and to grant it the legitimacy that is granted to other civil rights movements" (pp. 170-171). Amundson describes this "stigma of disability" and situates it in the context of broader "stigma theories," which he explains in the following terms:

> Stigmas are associated with *stigma theories*. These are ideologies: conceptual structures that rationalize particular beliefs about stigmatized groups, and make the disadvantages of these groups seem natural and inevitable. One aspect of the stigma of disability is the belief that UDIs (the disadvantages that are intrinsic to impairments) are immense, and that people with serious impairments are permanently disqualified from ordinary life by the immensity of their burden of UDIs (pp. 170-171).

Having laid out this conceptual and semantic background, Amundson now goes on to adduce a number of illustrative examples[12] that he takes to support his overall claim that those with impairments—and the DR movement that seeks to advocate on their behalf—are the objects

[12] These examples, Amundson says, are intended "to sensitize the reader (who may be unaware of the DR movement) to the difference between traditional views of disability and the views of modern DR advocates," for whom "[d]isability is regarded as neither shameful nor pitiable, but a fact of life that can be dealt with like any other fact of life" (p. 172).

of stigmatizing assumptions and therefore receive a lower level of respect than do other "disadvantaged" groups. For example, Amundson recounts an interview of actor John Cleese, in which Cleese relates his strategy for mocking authority figures: portraying them as disabled—specifically, as stuttering due to the effects of cerebral palsy. According to Amundson, this represents the intentional exploitation of a stigmatizing notion of "generalized incompetence"—one which, without further qualification, is clearly unwarranted and deeply offensive (pp. 173-174). Amundson also points in this context to a popular manual on screenwriting (Field, 1994), which (on Amundson's reading) encourages writers to use physical or other impairments as visual symbols of inward character faults. The problem with this, on Amundson's view, is that it both expresses and reinforces deleterious "stigmas of impairment," which in turn are embedded in "stigma theories." As Amundson puts it,

> [t]he media are widely recognized as expressing and promulgating stigmas of impairment.... Such notions are expressions of a stigma theory, an ideology. The stigma theory for physical impairment provides us with a code by which we can read character flaws out of impairments.... According to this ideology, everyone with a physical impairment either (a) is bitter and angry at the world because of their impairment, (b) got the impairment because of a character flaw and so somehow deserves it,[13] or (c) in some other mystical, fairy tale-like manner possesses a character flaw that is symbolically reflected in their impairment. There is no truth in this fairy tale; it is pure stigma.... The ideological connection of character flaw with visible impairments does immeasurable harm to people with impairments (pp. 172-173).

At the end of the day, Amundson insists, "stigma overrides logic" all too often in media portrayals of persons with impairments (p. 174).

These first two examples are intended to serve as prolegomena to the third and final example—treatment of the DR in the mainstream bioethics literature, as illustrated by *From Chance to Choice* (2000)—to which Amundson devotes the bulk of his critical attention. Specifically, Amundson examines how the DR movement is characterized by the authors of

---

[13] Cf. the discussion of the moral model approach to disability, in Ch. 2 of this work.

FCTC in the course of their rejection of the DR critiques of the "new genetics" (p. 175). Amundson identifies three arguments advanced by the authors of *FCTC* in support of his claim that "the DR movement has less moral legitimacy than other civil rights movements" (p. 175): the "Disadvantages Remain" argument, the "Not Unduly Burdensome" argument, and the "Meaning of 'Reasonable Accommodation'" argument, respectively.

Amundson begins his discussion of the "Disadvantages Remain" argument by identifying and quoting the specific text from chapter 7 of *FCTC* in which the argument appears. Labeling this paragraph "Case 4a," Amundson cites the text and highlights (by way of italics) certain key phrases in the passage, as follows:

> **Case 4a**. The limitations a gay or black person suffers are injustices in a quite uncontroversial sense: they are forms of discrimination. While deaf people and others with disabilities certainly do continue to experience discrimination, *they would continue to suffer limited opportunities even if there were no discrimination against them*. . . .The fact that it is costly to remove barriers of discrimination against blacks or gays has no moral weight because no one can have a morally legitimate interest in preserving unjust arrangements. . . . the costs of changing society *so that having a major impairment such as deafness imposes no limitations* on individuals' opportunities are not so easily dismissed. Those costs count from a moral point of view, because there is a morally legitimate interest in avoiding them [i.e. avoiding the costs] (*FCTC*, pp. 283–284, quoted in Amundson, 2009, p. 175, italics added by Amundson).

The central problem with this line of reasoning, Amundson argues, is that it misses entirely the "the point of the DR demand for justice" (p. 176). Amundson has no quarrel with the claim of the final sentence of the quoted paragraph—namely, that there is a "morally legitimate interest" in avoiding the costs (which would clearly be prohibitive) involved in attempts to change society to such an extent that impairments "produced absolutely no disadvantages to people who possessed them" (p. 176). Rather, Amundson challenges the claim that this is what the DR movement in fact demands (a demand which, if actually made by the DR movement, would rightly reduce its relative legitimacy). Instead, Amundson insists, the DR movement has always

distinguished between CDIs and UDIs (even if it has not always used those precise terms), and that "[t]he movement is *only* concerned to remove 'disabilities'—that is, CDIs" (p. 176)— rather than UDIs, which, the DR movement is happy to acknowledge, may accompany certain types of impairment regardless of what social changes are made. In other words, the DR movement is focused on removing only those disadvantages associated with impairment that are caused *by society*— CDIs—rather than the (impossible) task of eliminating *all disadvantages whatsoever* that may happen to be associated with impairments. (This point turns on the distinction made earlier between the biomedical condition itself—"impairment"—on the one hand, and the disadvantages, whether CDIs or UDIs, that *accompany* or are *associated* with impairments.) At the end of the day, Amundson says, "[t]he general attitude of the [DR] movement is that impairment, in and of itself, is something that we can live with" (p. 176)—all the movement asks is that those disadvantages that are unnecessarily and unwarrantedly caused by society (the CDIs) be removed by changing society accordingly.

To be sure, Amundson acknowledges, this raises yet again the difficulty of "drawing the line" between CDIs and UDIs. Nevertheless, "drawing the line between *what is* and *what is not* society's responsibility is a problem for all civil rights movements, not only for DR" (p. 176). Thus, Amundson concludes, "the mere fact that some impairments involve UDIs makes absolutely no difference to the legitimacy of DR as a civil rights movement, contrary to the quoted argument from FCC" (p. 176).

The second argument advanced by the authors of *FCTC*—what Amundson labels the "Not Unduly Burdensome" argument—is encapsulated in the following quotation (with italics again added by Amundson):

> **Case 5**. Our society has learned through its efforts to accommodate people with disabilities that in many cases lowering the barriers to participation *need not be unduly burdensome* to others (*FCTC*, p. 320, quoted in Amundson, 2009, p. 177, italics added by Amundson).

This statement, Amundson argues, is misleading in that it implies that the barriers to full participation in society faced by persons with impairments are "high standards" that are

nonetheless justified in principle; society could, then, afford to "lower" those standards without such lowering being "unduly burdensome to others" (the non-impaired population). The problem with this, however, is that

> according to DR activists, the barriers to the participation of people with impairments are not high standards at all. Instead they are arbitrary barriers and obstructions in the environment that serve no legitimate purpose at all. So the phrase "lowering of barriers" already encourages a misleading notion of barriers in the context of DR (p. 177).

In order to see this more clearly, Amundson invites us to consider the following cases that parallel case 5 both in structure and in content. What would we be inclined to say about these statements?

> **Case 5a.** Our society has learned through its efforts to integrate people with disabilities into the workforce that in many cases doing so need not be unduly burdensome to others.
>
> **Case 6**. Our society has learned through its efforts to integrate women into the workforce that in many cases doing so need not be unduly burdensome to men.
>
> **Case 7**. Our society has learned through its efforts to integrate African Americans into the workforce that in many cases doing so need not be unduly burdensome to white Americans (Amundson, 2009, p. 177).

Clearly, Amundson argues, Cases 6 and 7 would be taken to be condescending and demeaning were they to be uttered by academics with reference to movements to secure equality in the workforce for women and blacks. Yet, oddly enough, the acceptance of Case 5 (above) would seem to entail an acceptance of Case 5a as well. But if Cases 6 and 7 are illegitimate—as Amundson takes the academy to have concluded—why then should Case 5a be considered legitimate, given its similarity in structure and content? To put the point more bluntly, the logic of Case 5—and its corollary in Case 5a—makes it the case that "[t]he only way disabled people can justly expect integration (according to the authors of Case 5) is if integration is not unduly burdensome *to nondisabled people*!" (p. 178). But such logic, if applied to the cases of women and blacks (Cases 6-7) would be rejected outright—so why then it is accepted when applied to

the case of the disabled (Cases 5 and 5a)? The only explanation that makes sense, on Amundson's view, is that there is a bias in the academy against the legitimacy of the DR movement. As Amundson sums up his critique of this argument,

> Case 5 would not have been made by a genuine advocate of DR. It is a condescending and divisive statement by a nondisabled person, acknowledging only that *sometimes* the rights of *those* disabled people do not harm *us.* Only in the case of disability rights is the academy so backwards in its thinking (p. 178).

Finally, Amundson considers the third argument advanced by the authors of *FCTC*, which focuses on "the meaning of 'Reasonable Accommodation.'" The argument relies upon the principle embedded in the following paragraph:

> **Case 4b**. The fact that it is costly to remove barriers of discrimination against blacks or gays has no moral weight because no one can have a morally legitimate interest in preserving unjust arrangements. (Achieving a fair distribution of the costs of reform is another matter, of course.) (*FCTC*, p. 284, quoted in Amundson, 2009, p. 178)

The principle at play here—to which Amundson has no objection—is that while "no one can have a morally legitimate interest in preserving unjust arrangements" (hence rendering the cost of barrier removal morally irrelevant to the question of whether or not such barriers *ought* to be removed), justice also requires that the *distribution of costs* imposed by the removal of discriminatory barriers be fair as well. That is to say, if the removal or alleviation of certain discriminatory barriers is likely to impose disproportionate costs on particular segments of society, then it may be appropriate to (at the very least) delay the implementation of the necessary changes or accommodations, even if such changes are themselves demanded by justice. Or, to put it differently, "the reform of injustices must be designed not to create too many new injustices, and if such reforms cannot be devised, then the old injustices may 'justly' remain in place longer than they would if a just reform were possible" (p. 179).

The problem, as Amundson sees it, is that the authors of *FCTC* are inconsistent in their application of this principle when it comes to their treatment of the DR movement. We can see this, Amundson says, in their discussion of the meaning of "reasonable accommodation" as it

features in legislation such as the Americans with Disabilities Act (1990). In this context, Amundson quotes the authors of *FCTC* once again:

> **Case 8**. It is important to emphasize that the ADA adds the qualifier that all that is required in the name of equal opportunity is 'reasonable' accommodations. The addition of this qualifier signals a recognition that the interest of employers, of workers who do not have disabilities, and of consumers of the goods and services that public and private organizations produce are also legitimate and should be accorded some weight (Amundson, 2009, p. 179, quoting *FCTC*, p. 292).

The authors of *FCTC*, Amundson goes on to argue, interpret "reasonable" primarily with reference to the "moral legitimacy of those who oppose equal access" (p. 180). In other words, "reasonable" ends up being understood in terms of (or from the perspective of) *those who oppose accommodations:* if particular accommodations appear "unreasonable" to certain parties, then that judgment must be accorded moral "weight." The problem with this, however, is that this interpretation effectively renders the term "reasonable accommodations" equivalent to the claim that "employers *do have* a legitimate interest in preserving the unjust segregation of disabled people, even though the same employers *do not have* a legitimate interest in preserving the unjust segregation of blacks, gays, and women" (Amundson, 2009, p. 179).[14] This, Amundson says, is clearly inconsistent, an "obvious double standard" (p. 180).

Rather than approaching the DR movement from this angle, Amundson counters, the authors of *FCTC* had available to them a perfectly good alternative, one that would acknowledge the difficulties involved in accommodating those with impairments while at the same time upholding the (equal) moral legitimacy of the DR movement. Specifically, he says, the authors of *FCTC* could simply have appealed to the principle expressed in Case 4a (see above). On this approach, "[t]he reference to *reasonable* accommodation need not mark the moral legitimacy of those who oppose equal access. Instead, it marks the difficulties in achieving a fair distribution of the *costs* of reform" (p. 180). That is, just as they do with respect to women and racial minorities, the authors of *FCTC* could affirm the full moral legitimacy of the DR claims for justice, while also

[14] Of course, it is not entirely clear that the authors of *FCTC* would agree with the characterization here of the "segregation" of disabled people as *unjust*. Indeed, this seems to be precisely the point in dispute!

acknowledging that the costs involved in making the requisite social changes may sometimes necessitate that those changes be delayed or otherwise attenuated. The fact that the authors of *FCTC* do *not* take this approach, Amundson concludes, lends credibility to the suspicion that the DR movement as such enjoys a lesser degree of "moral legitimacy" in the academy than do other disadvantaged groups. In the final analysis, "[t]he DR movement does not share the legitimacy of other civil rights movements. There are many claims for equal access to the goods of society, but some are more equal than others" (180).

B. What Causes Disability Stigma?

Operating on the assumption that there *is* such a thing as "disability stigma"—that is, persons with disability *are* stigmatized, on at least some occasions—it is worth our while to inquire as to the *cause* (or causes) of such stigmatization. As one might expect, theories abound as to the relevant causal factors involved in stigmatization of the disabled. We shall consider three major representative samples here.

1. Displaced fear/abjection

One prominent theory is that the source of the "hostile reactions" of nondisabled people toward disabled persons is a fear that the former have of the latter. According to Jenny Morris,

> [o]ur disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from common humanity; [we are] treated as... alien. Having put up clear barriers between us and them, nondisabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity (Morris, 1991, p. 192, quoted in Silvers, 1998, p. 44).

The basic idea here is that the nondisabled feel threatened by the possibility that they, too, may someday become disabled—hence, they shun the presence of disabled persons. Anita Silvers cites social philosopher Iris Marion Young along similar lines. According to Silver's reconstruction of Young's argument, Young locates the source of the exclusion and stigmatization of the disabled in a "process of abjection, wherein we experience as permeable the boundaries that

heretofore have seemed to separate us from people we think of as inferior to ourselves" (Silvers, 1998, pp. 43-44). As Young puts it,

> I cannot deny that the old person will be myself, but that means my death, so I avert my gaze from the old person, or treat her as a child, and want to leave her presence as soon as possible. My relationship to disabled people has a similar structure. The only difference between myself and the wheel-chair bound person is my good luck. Encounter with the disabled person again produces the ambiguity of recognizing that the person whom I project as so different, so other, is nevertheless like me (quoted in Silvers, 1998, pp. 43-44).

In other words, on Young's account, there is a two-step process here. First, the nondisabled person in some sense identifies her (present or future) self with the disabled person. Then, since that identification is painful and uncomfortable (because it reminds the nondisabled person of her own mortality and potential for morbidity) the nondisabled person represses that identification—with stigmatization, isolation, and social exclusion being the inevitable results.

2. Cognitive mistake/failure to identify with the disabled

In opposition to the theory just described, Silvers argues that "it is improbable that nondisabled people first identify with, but then repress their resemblance to, people with disabilities." Instead, she says, "[t]he evidence is that they never identify with them at all" (Silvers, 1998, p. 43-44). After adducing evidence in support of this claim, Silvers argues to the conclusion that "[n]ot displaced fear but rather a commonplace cognitive mistake—namely, the failure to weigh realistically the likelihood that in the future one might suffer undeservingly—degrades the compassion with which the nondisabled might otherwise engage individuals with disabilities into distancing pity" (Silvers, 1998, p. 48).

3. Analysis and critique of the positions

Silvers is surely correct when she argues that not all cases of disability stigma can be attributed to *fear of* or *abjection from* the disabled. One could, for example, see someone as pitiable, or hateful, without also *fearing* that person: one might view a homeless person as being *pitiable* while not *fearing* that individual. Arguably, one might even be motivated by a more "noble"

emotion than pity or hate—say, feeling compassion for an individual—yet nevertheless engage in actions that have the *effect* of stigmatizing that individual. Moreover, if the social model critics are correct in their claim that much (if not all) of the discrimination and stigma suffered by disabled persons is the result of social structures and arrangements, then to the extent that such stigma is so attributable, to that extent it *cannot* be attributed directly, or at least not exclusively to *fear* or *abjection.* In short, it seems patently false to attribute *all* stigmatization of the disabled to *fear of* the disabled.

On the other hand, it seems that Silvers is only partially correct. While it may very well be, as she claims, that stigmatization of the disabled often stems from a basic "cognitive mistake," a failure to identify with the disabled, it cannot be the case that *all* stigma is so attributable. For one thing, although we have just adduced cases in which "fear" or "abjection" is *not* plausibly seen as the primary motivating factor underlying stigmatization of the disabled, it seems that we can also plausibly adduce cases in which fear *is* the best causal explanation for such stigma. Consider, for example, disabilities involving visible physical disfigurement. This form of disability, and the stigma resulting from it, has been a staple of numerous famous works of art: *The Hunchback of Notre Dame, The Phantom of the Opera*, and *Frankenstein* come to mind immediately. Less fanciful, yet no less seriously stigmatizing, are the burdens borne by those who suffer from severe birth defects or burns. In cases such as these, it seems improbable that the source of stigmatization of such individuals is to be found in the fact that we fail to assess realistically our own likelihood of finding ourselves in such a situation (as Silvers suggests)—after all, these would seem to be paradigm instances of cases that, all other things being equal, *are* unlikely to happen to most of us. Most of us will *not* be severely burned at any point in our lifetime, and, if we have not *already* been born with a severe birth defect, the likelihood of our developing a severe physical deformity (due to, say, genetic causes, accident, or trauma) at some later point in our lifetime is relatively slim. So, it seems implausible to attribute our stigmatization of such individuals to the sort of "cognitive mistake" to which Silvers refers. More likely causal candidates include precisely the sorts of things to which Young directs our attention—namely, "fear" or "abjection" (we *fear* that which is markedly different from us), or, perhaps, a more deep-seated

antipathy toward that which is "ugly" or otherwise aesthetically unappealing. This is not, of course, to excuse such stigmatization: it is, rather, to argue that stigmatization of the disabled cannot always be attributed (only) to a "cognitive mistake." Sometimes such stigmatization *really is* the result of fear or some other base emotion (such as revulsion, pity, etc.).

Similarly, one might stigmatize, e.g., the homeless without such stigmatization being attributable to a failure to assess realistically the chances of one's someday being homeless oneself—it seems plausible that most people (at least in industrialized Western societies) can reasonably expect *not* to be homeless someday. Yet, one might still stigmatize a homeless individual, or "the homeless" as a class. To what, then, should such stigma be attributed? Perhaps one *is* fearful of the homeless—"is it safe for my daughter to walk down the street with these homeless bums milling about?"—or perhaps it is attributable to some other factor: say, pity ("those poor wretches") or some aesthetic value ("those bums are a blight on this beautiful neighborhood"). In any event, it seems implausible to claim that stigmatization in these sorts of cases is due to the "cognitive mistake" to which Silvers draws our attention. For, as we have just shown, there are at least some instances in which the stigmatized condition *really is* unlikely to be visited upon the one doing the stigmatizing—in which case the latter individual cannot be faulted *for judging it unlikely that she will find herself in that same sort of situation*. That is to say, the judgment (concerning the future likelihood of finding oneself in the same sort of situation) is entirely reasonable, and yet *we fault her for stigmatizing the individual in question*. Thus, we cannot appeal to the "failure to identify" as the blameworthy causal factor underlying the stigmatization.

C. The Medical Model and Disability Stigma

1. The allegation: the medical model of disability stigmatizes the disabled

As we have seen, it is a commonplace in the contemporary disability rights literature to distinguish between two "models" of disability: the so-called "medical model" and the "social model" of disability, respectively. Ron Amundson takes the latter model to be a "defining characteristic of the disability rights movement," a model which, on his reconstruction of it, explains the disadvantages associated with disability "as effects not of biomedical conditions of

individuals but of the socially created environment that is shared by disabled and nondisabled people" (Amundson, 2005, p. 101).

This "social model" of disability contrasts sharply with the so-called "medical model" of disability, which Bill Hughes characterizes in the following terms: *"The ontological essence of disability is a physical or mental impairment or a biological 'deficit' or 'flaw' that limits what disabled people can do"* (Hughes, 2002, p. 60, italics in original). The conceptual core of this model, according to Hughes, is the underlying assumption that biophysical "abnormality" or "maladaptation" somehow *leads to* or *causes* social "abnormality" or "maladaptation":

> In other words, to be defined as a "flawed" body is simultaneously to be defined as incapable of adequate social participation. The corporealization of disability [means], in practical terms, the segregation of those so labeled. The logic of the medical model runs from diagnosis to social response. In causal terms, there seem to be three linked elements in the chain: impairment leads to disability, which in turn leads to confinement or "institutionalization" (Hughes, 2002, p. 60).

This is, at root, another way of putting the central charge that advocates of the social model of disability lay at the feet of the medical model of disability—namely, the claim that the medical model effectively *stigmatizes* (in the sense of exclusion, marginalization, or segregation) the disabled.

2. Analysis and critique of the allegation

The central thesis of this section is that it is a mistake to say that the medical model is to blame for stigma—that is to say, there is no *necessary connection* between the "medical model of disability" and stigma. To see why this is the case, it will be helpful to recall the key claim of the unconstrained social model of disability—namely, that "disability" is (solely) the result of "flawed" or "oppressive" social structures and arrangements, rather than the result of a "flaw" or "defect" to be found in the disabled individual.[15] Upon closer inspection, this claim is more difficult to make out than it might at first appear. For example, in the context of her critique of the "medical model

[15] As Silvers puts it, "[t]he [social] model [of disability] explains the isolation of people with disabilities not as the unavoidable outcome of impairment but rather as the correctable product of how such individuals interact with stigmatizing social values and debilitating social arrangements" (1998, p. 76).

of disability," Silvers acknowledges that the degree of social limitation an individual with a disability experiences is a function of "complex interactions between the individual's limits and the limits of her environment." This, she says, accounts for "why it is so difficult not only to predict the degree to which but also to comprehend the process whereby physical dysfunction leads to social dysfunction." Further, Silvers takes this as a reason to adopt the "social model" of disability over against the medical model—as she puts it, "[t]his is... why it is misleading to assume that the misfortune of disablement must be due to natural rather than social agency" (Silvers, 1998, p. 63). But of course, if Silvers is correct in her claim that the degree of social limitation that a disabled person experiences is, in her own words, the outcome of a set of "complex interactions" between individual and environmental limits, then her argument cuts both ways: why assume that "disability" (and its limiting effects) is due *only* to social agency, as the "social model" of disability claims?

The reality, it would seem, is considerably more complex. Indeed, as David Wasserman argues, it is in fact quite difficult to draw a clear distinction between "natural and socially produced disadvantage" in general, since the degree of disadvantage experienced by any particular individual is in large part a function of which "cooperative schemes" are adopted in a given society. Drawing a coherent boundary between these different kinds of disadvantage is especially difficult in the case of disabilities, Wasserman argues, since

> they involve, by definition, an interaction between a person's 'natural endowment' and her environment. The social environment is involved at two levels: first, in helping to determine, through rearing and education, the traits a person will acquire; second, in determining how useful those traits will be to the pursuit of various goals....

In short, Wasserman concludes,

> the problem is not that we cannot make useful generalizations about whether specific biological characteristics are advantageous or disadvantageous across the range of possible social environments, it is that we lack any natural baseline with which to compare the effects of various cooperative schemes (Wasserman, 1998, pp. 162-163).

But, of course, if these latter claims are correct, then we have further reason to question the truth of the aforementioned allegation leveled against the medical model of disability. Instead, we should conclude that *both* "natural" and "social" factors are involved in the disability phenomenon, and that there is therefore no *necessary* connection between the medical model and stigma..

D. Preventing Stigmatization of the Disabled

By way of preliminary comments, it is worth noting that we might envision at least three general sorts of responses to the charge that the medical model stigmatizes the disabled. First, one might ask the question, if the medical model is a *causal* explanation, how could it *possibly* stigmatize? That is, one might argue that if the medical model offers a reductionistic causal explanation for disability (given in terms of underlying biological, anatomical, and physiological processes and structures), then there is no room for the infiltration of *moral* values into that causal explanation—hence, no room for stigmatization *on the basis of the medical model.* Second, even if one grants that the medical model *sometimes* has the effect of stigmatizing the disabled, it does not follow that it *always* does so. Indeed, it can be argued that, in fact, stigmatization is by no means a *necessary* consequence of the medical model. This can be argued by adducing historically salient counterexamples to demonstrate that, in at least some cases, the medical model may be seen to have the *opposite* effect—namely, that of *reducing* the degree of shame, stigma, and the like, associated with disability. Consider, for example, the transition from viewing stomach ulcers as stress-related (moral model) to seeing them as caused by viral infection (medical model). Could it be the case that viewing *disability* in similar ways (i.e., in medical rather than social or moral terms) might actually help to *alleviate* problems with stigmatization of those with disabilities? In other words, might not the medical model be, in at least some cases, an effective *antidote* to the excesses of or problems associated with the moral and social models? Is it possible that, at least on some occasions, medical reductionism might have *advantages* when it comes to the treatment of patients?[16] Third, and perhaps most

[16] I am grateful to Laurence B. McCullough, who pointed this out in personal conversation.

importantly, the medical model may be *neutral* toward but not a *buttress* against stigmatization of the disabled.[17]

With those preliminaries out of the way, we can now move on to consider, more specifically, the prospects for avoiding and/or ameliorating stigmatization of the disabled. In that regard, we note that the foregoing discussion highlights at least two important implications. First, if the causes of disability stigma are multiple rather than singular, then multiple approaches may be required to ameliorate it. Strategies that work for ameliorating *fear* may or may not be effective for ameliorating nondisabled persons' *failure to identify* with disabled individuals, and so forth. Second, if the medical model of disability does not *itself* stigmatize the disabled—or at least if it need not be taken *necessarily* to stigmatize them—then we may very well be able consistently to accept the legitimacy of the medical model as such, while resisting the temptation to respond to its findings in ways that have the effect of stigmatizing the disabled. In other words, if the medical model is, taken by itself, neutral with respect to stigmatization, then our attention is more properly directed toward determining what are the appropriate *responses* to the pronouncements of the medical model. Our emphasis then would be on placing constraints on stigmatizing *responses* to the findings of whichever model of disability we adopt (whether "social," "medical," or otherwise).

Thus, the ultimate question is not which model of disability we ought to adopt but, rather, how we ought to respond to the findings or pronouncements of a given model of disability. Just as it is still open to us to debate how best to change particular social structures that are deemed by the social model of disability to be "oppressive," so it would also seem that even if we take the medical model to locate the source of disability in the individual, we would still find ourselves faced with choices as to how best to *respond* to that finding. It would then be open to us to argue that certain forms of response are inappropriate responses to the medical model, even if we grant the legitimacy of the medical model as such.

How, then, might we guard against stigmatizing responses to the medical model and/or disability in general? On the one hand, it would appear that Silvers is right to question the fairness of the disparity in the "burden of proof" placed upon disabled persons to prove the "value of their

[17] I owe this last observation, in particular, to H.T. Engelhardt, Jr. (in personal conversation).

presence and participation" in society (Silvers, 1998, pp. 86-88). A first step toward reducing stigmatization of the disabled, then, would be to take more seriously the self-reports of those who live with disabilities—after all, why should the judgments of the nondisabled concerning the "quality of life" of those with disabilities be permitted, *a fortiori*, to trump those of disabled persons themselves? At the very least, such judgments ought to be weighed fairly against the self-perceptions of those who actually live with the disabilities in question.

There is, of course, considerable debate concerning the appropriate means whereby to ameliorate the disadvantages suffered by disabled persons as a consequence of their disabilities and/or the stigma attaching to such disabilities. Proposals run the gamut from the strongly egalitarian positions of Robert Veatch, Norman Daniels, and others, according to which the "defects" borne by disabled persons ought to be "repaired" if possible, in an effort to restore them to a "normal" level of functioning—and if such "repair" is not possible, then disabled persons ought to be compensated directly for the disadvantages accruing to them as a result of their inability to be so "repaired." Anita Silvers, on the other hand, argues that rather than compensating disabled individuals directly, social structures and arrangements ought to be altered in such a way as to provide disabled persons with full (or at least fuller) opportunity for participation in social life—a sort of indirect rather than direct compensation. Taking a more or less "middle of the road" approach, David Wasserman argues that in some cases the *individual* ought to be altered, while in other cases *society* should be changed, in order to provide disabled persons with the greatest possible range of opportunities consistent with the limited resources available to all (disabled and nondisabled alike).[18]

Even staunch egalitarians such as Robert Veatch recognize, however, that there are dangers inherent in any attempt to ameliorate the disadvantages of disability—and particularly so with an egalitarian approach that requires direct compensation to individuals. Along these lines, Veatch identifies what he terms the "paradox of egalitarianism":

> A commitment to egalitarianism equality taken seriously may actually identify those to be stigmatized and even provide a kind of point total (measured in dollars or services to be

[18] These respective approaches have been discussed briefly, along with relevant source citations, elsewhere in this work.

> provided to each) that could mark the extent of the stigma. The result could actually be a greater, more identifiable discrimination against the handicapped.... the very fact that we are singling out people for compensation for their handicaps stigmatizes them as being different, and almost inevitably that difference is interpreted as inferiority. Thus striving for equality produces stigma and stigma produces feelings of inferiority and therefore inequality (Veatch, 1986, p. 189-190).

At the end of the day, Veatch concludes, "[e]quality may be self-defeating": our very attempts at ameliorating stigma may in fact perpetuate it Veatch, 1986, pp. 189-190).

For Veatch, the solution to the "problem of stigma" is to be found in "destroying the 'we/they dichotomy." Stigma, he says,

> results in a sense of satisfaction that derives from dividing the world into a 'we' and a 'they' and judging rightly or wrongly that the characteristic that the 'we' possess is superior to the one that the 'they' possess.... The communitarian perspective implied in the premises underlying the Judeo-Christian and secular egalitarian tradition does not attack the value judgment. Instead, it attacks the process of dichotomizing, of separating the world into the 'we' and the 'they' (Veatch, 1986, p. 199).

Thus, as Veatch would have it, if we acknowledge that we are *all* (in some sense and to some degree) "handicapped," then we will no longer feel the need to divide the world into a "we" and a "they," where the former stigmatize the latter because of their status as "handicapped."[19] But this has its problems, chief among them being that it guts the concept of "handicap" of any usefulness whatsoever—for if we are *all* "handicapped," then none of us is *really* handicapped, and the concept loses its practical meaning and import. In other words, this move simply *renames* or *relabels* the problem, for clearly some will be *more* "handicapped" than others—once again resulting in distinctions among groups. It appears, then, that we cannot dispense with the notion of "the handicapped" or "the disabled" as being somehow a distinct class, in some sense separate from, or different than, the rest of society.

---

[19] Veatch puts the point this way: "Since all are in this situation, all are in one class. Everyone is handicapped; no one is part of the group we call 'they,' no one should be stigmatized" (Veatch, 1986, p. 200).

Perhaps, then, we need to rethink the matter altogether. Perhaps the fundamental consideration when it comes to preventing stigmatization of the disabled is not whether we should aim for "formal justice" (Silvers), "distributive justice" (Wasserman), or an egalitarian ideal (Veatch/Daniels, etc.), or whether we should think of disability in terms of the "social" or "medical" model of disability, or some other model altogether. Instead, the fundamental question is how we ought to *respond to* the disabled, regardless of how we conceptualize disability, and regardless of what theory of justice we ascribe to.

All of this having been said, it is important to emphasize that the question of how one *conceptualizes* disability remains a separate issue from the question of how we, either individually or as a society, ought to *respond* to disability. Thus, for example, *even if* one *does* view disability as a "defect" in (or of) the individual who bears a disability—in which case one might argue that corrective or reparative therapy is warranted—it certainly would not *follow* that that individual ought to be *eliminated* or her existence prevented altogether (as in prenatal testing coupled with selective abortion on the basis of disability, for example; cf. our discussion, earlier in this work, of the "abortion presumption"). So, the real question is not which model of disability we ought to adopt—it may be that more than one model of disability is simultaneously correct (cf. Silvers, 2009)—but, rather, how we ought to respond to the findings or pronouncements of a given model of disability.

IV. CONCLUSION

A few very brief comments are in order as we bring this chapter's discussion to a close. After engaging in an extended discussion of the "stigma" objection and some of its ramifications, the reader may be left asking the following two questions: (1) Does the BPS approach advocated in this work survive the "stigma" objection discussed in this chapter? and (2) Can the BPS approach advocated in this work *help* in dealing with the problem of stigmatization of the disabled? Our answers to this question should by now be both predictable and supported by all the work that has gone before. Clearly, we will answer the first question in the affirmative; here, our argument can be summed up by saying that if there is no *necessary* connection between the

medical model and disability stigma, then the BPS approach can safely incorporate the insights of the medical model without thereby being subject to the charge of stigmatizing the disabled. Perhaps more interestingly, the second question can also be answered in the affirmative. Here, the basic idea is likewise one that has surfaced numerous times already—namely, that by drawing attention to the *multiple* dimensions in terms of which the disability phenomenon must be understood, the BPS approach helps to buttress against the tendency to focus solely (and, potentially, in a *stigmatizing* kind of way) on one dimension to the exclusion of other relevant dimensions of the disability experience.

Chapter 7

THE CONCEPT OF DISABILITY: IMPLICATIONS AND AREAS FOR FURTHER RESEARCH

I. INTRODUCTION

The main tasks of this chapter are three-fold. First, we review and summarize the key points of this work's argument thus far, with a view toward painting the "big picture"—that is, how the different levels of explanation in a BPS account "fit together" into a coherent, unified whole. Second, we identify a number of implications of this work's findings for our understanding of disability generally, for the disability rights (DR) and disability studies (DS) movements in particular, and for the relationship between the disabled and the broader society. Finally, this chapter concludes by identifying some remaining questions and potential avenues for further research that are suggested by this work's explorations. In this context, we also discuss how this work fits into a larger research program, of which it is only the first stage.

II. THE "BIG PICTURE": HOW THE LEVELS OF EXPLANATION IN A BPS ACCOUNT "FIT TOGETHER"

In this work we have drawn attention to three distinct levels of explanation at which the phenomenon of disability can be accounted for. At the *biological* level (Ch. 4), we found that impairment is objectively real, ontologically speaking, and that since disability is grounded in impairment, it too is also objectively real. We put this in terms of the language of predication, by saying that both impairment and disability involve "intrinsic" predication at the biological level of explanation. At the *psychological* level of explanation (Ch. 5), we explored some of the ways in which non-moral normative—(specifically aesthetic, cultural, and epistemic) values or considerations enter into identifications of states of affairs as "impairment" and/or "disability." And at the *social* level of explanation (Ch. 5), we saw that moral normative considerations shape the character of the lifeworld in which persons with disabilities live. This is seen most clearly when we consider the "dominant cooperative framework" in terms of which a society is organized, for the structure of the dominant cooperative framework has a direct impact on both opportunities and outcome—that is to say, there is a dynamic interplay between objectively real impairment and the dominant cooperative scheme, such that disability may or may not result, depending on the

nature of that interaction. This in turn raises crucial questions of social justice regarding how society ought to *respond to* conditions designated as 'impairment' or 'disability'—in particular, questions having to do with the choice between "inclusive" and "exclusive" cooperative schemes. The central issue underlying these choices is the question of whether or not the "morality of inclusion" entails an obligation on the part of society to promote inclusion, and if so, how far that obligation extends. Combining these individual levels of explanation into a single, aggregated picture, we find that disability *emerges* out of these levels of explanation: disability is grounded in the ontological reality of impairment, with an ingression of non-moral normative values, and further appreciated in light of moral normative considerations.

At this point we need to say a bit more about how the different "levels of explanation" to which we have drawn attention in this work fit together—that is, how they relate to and interact with one another. It will be helpful for this purpose to briefly recall what we said in Chapter 2 regarding the relationship between the *levels of explanation* of a BPS account, on the one hand, and the *domains of philosophical inquiry*, on the other. As we said in that context, at the *biological* level, a BPS approach to disability will offer an *ontological* explanation of the realities involved in the disability phenomenon. At the *psychological* level, a BPS approach will offer a *non-moral normative* explanation. And, at the *social* level, a BPS approach will offer a *moral normative* explanation.

The first thing to note about the levels of explanation is that they are each *individually necessary*, and only *jointly sufficient*, for a full, complete explanation of the disability phenomenon. At the *biological* level of explanation, impairment and disability are properly characterized *ontologically* in realist terms. However, an ontological account alone does not identify for us all the relevant grounding assumptions that play a role in identifying certain states of affairs as states of impairment and/or disability—for that we need the *psychological* level of explanation, which encompasses a range of *non-moral normative* considerations. Even then, however, this does not tell us how social responses (attitudes/practices, etc.) either enter into such identifications or shape the experiences of those conditions so designated as impairment and/or disability. For insight into those realities, we need the *social* level of explanation, at which

various *moral normative considerations* come into play. Only by attending to the realities identified at each of these levels of explanation, and holding them together in a single account, can we properly characterize either impairment or disability. We can represent this schematically as follows:

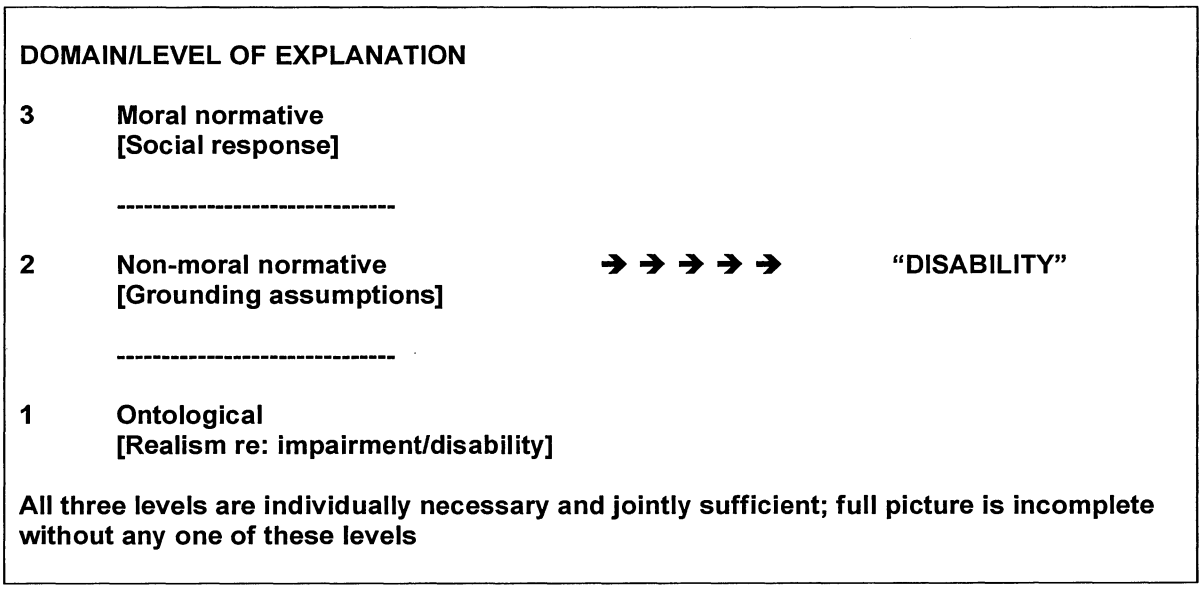

Fig. 7.1 Relationship of levels of explanation in a BPS account.

Another route to getting at the ways in which the different levels of explanation relate to and interact with one another is to identify the *key question,* or *issue*, that is addressed at each level. Approaching the topic from this angle yields the following results. At the *biological* level of explanation, the key question is whether or not impairment should be understood in realist or nonrealist terms. As we have seen throughout this work, the answer to this question has far-reaching implications for what one goes on to say about the nature and import of the 'disability' designation. At the *psychological* level of explanation, the key question is the extent of ingression of non-moral normative values—aesthetic, cultural, and epistemic—into identifications of states of affairs as impairment and disability. The key question at the *social* level of explanation is the moral normative question of the appropriate social response to disability. As we saw in Chapter 5, answers to this question will turn in large part on assumptions regarding whether or not "disadvantage" is *inherent* to disability, or whether that relationship is contingent at best. Although a full exploration of the issue of the appropriate social response to disability has been reserved

for a subsequent work, the findings of this study permit us to make the following general observations. We have shown in this work that there is no *necessary* connection between conceptualizations of disability, on the one hand, and particular social justice claims on the other. As we will argue later in this chapter, this need not be seen as threatening to the community of persons with disabilities. In fact, this arguably has the effect of *truly* "leveling the playing field" by prohibiting *both* positive and negative prior assumptions regarding the legitimacy of social justice claims on behalf of the disabled. Here again, our overall conceptualization of disability will be a function of how one answers each of these key questions.

We can represent schematically this relationship between the levels of explanation in terms of the following diagram:

DOMAIN/LEVEL OF EXPLANATION		KEY QUESTION/ISSUE
3	**Moral normative [Social response]**	**What is the appropriate social response to disability...?**

2	**Non-moral normative [Grounding assumptions]**	**Is disadvantage inherent to disability...?**

1	**Ontological [Realism re: impairment/disability]**	**Should impairment/disability be understood realistically or nonrealistically?**

Conceptualization of disability flows out of how one answers these key questions/issues

Fig. 7.2 Key questions at each level of explanation in a BPS account of disability.

Finally, we can ask the question, "what is it that each level of explanation *gives* or *provides* to us?" In other words, why do we *need* each level of explanation? Our answer to this question will run along the following lines. The *biological* level of explanation, by emphasizing ontological realism regarding impairment, provides us with a criterion (not necessarily the *only* criterion) for *identifying* cases of impairment, and by extension, disability. By ferreting out the relevant non-moral normative grounding assumptions in terms of which states are identified as

impairment or disability, the *psychological* level of explanation provides us with a tool for *interpreting* the meaning and significance of impairment and disability. And, finally, in highlighting issues having to do with the relationship between the disabled and society, including the basic cooperative framework and the questions of prevention versus/and/or accommodation, the *social* level of explanation provides us with resources to tease out both (1) the role played by various social factors in the production, exacerbation, and/or amelioration of disability states, and (2) the actual—and, perhaps, the ideal—scope of appropriate *social responses* to disability. These relationships can be represented schematically as follows:

DOMAIN/LEVEL OF EXPLANATION...		WHAT EACH LEVEL PROVIDES...
3	**Moral normative**	**Relationship between disabled & society** **-- Basic cooperative framework** **-- Generation/exacerbation/amelioration** **-- Prevention VS./AND/OR accommodation** **➔ SOCIAL RESPONSE**

2	**Non-moral normative**	**Grounding assumptions** **➔ INTERPRETATION**

1	**Ontological**	**Realism re: impairment** **➔ IDENTIFICATION**

Fig. 7.3 What each level of explanation in a BPS account provides.

III. IMPLICATIONS OF THIS WORK'S FINDINGS

The findings of this work have important implications in at least three major areas: (1) understanding the concept of disability; (2) the future of the academic field of disability studies (DS); and (3) the future of the disability rights (DR) movement and the relationship between the disabled and the broader society.

A. Implications for understanding the concept of disability

With respect to the so-called "models debate" regarding the concept of disability, one implication of this work's explorations is that we can reject the strict "either-or" dichotomies—medical model versus social model; medical intervention versus social changes, etc.—that have tended to characterize the disability literature. Instead, a BPS approach can accommodate, and

account for, a "both-and" explanation of and response to the disability phenomenon. From an explanatory point of view, the BPS approach explains both why we try to avoid disability—namely, it *does* involve *real* loss—but also why disability need not be conceived as inherently "opportunity-limiting," i.e., as involving an *overall* loss of opportunity—specifically, loss at the ontological level does not necessarily entail loss at the psychological or social levels, nor does loss at any of these individual levels necessarily entail an *overall* loss of value. In this way, the BPS approach accounts for what is correct about each side of the various disputes (medical versus social model; Brock vs. Amundson; etc.) discussed in this work, while also capturing what those individual accounts miss.

Another way to put this point is to say that both sides of the "medical versus social model" debate need to modify their views; they are both partly correct and partly incorrect. On the one hand, so-called "medical model" advocates—i.e., critics of unconstrained versions of the social model—are correct insofar as they claim that impairment involves a *real* loss (i.e., disability is not a "neutral variation"). On the other hand, disability rights activists and scholars—many of them advocates of a "social model" approach to disability—are correct to challenge the *definition* of disability as inherently "opportunity-limiting," and to challenge the practical implications (particularly for social and public policy) that allegedly flow from such a definition of disability.

B. Implications for the future of the disability studies (DS) movement

In light of the above, there is an important implication for the academic field of disability studies (DS) as well. That implication, in a nutshell, is that DS needs to accept the objective ontological reality of impairment as such. Crucially, however, acknowledging this reality, and the reality that disability as such is disvaluable, need not be inherently threatening to persons with disabilities, because negative value judgments can be *constrained* by a BPS account. This constraint can be effected by embracing the "disadvantage *simpliciter* versus disadvantage on balance" distinction, which we discussed in the context of Steinbock's evaluation of the "neutral variation" view (see Ch. 4). Here, the basic idea is that while disability may, taken by itself, involve real disadvantage, it does not follow from that fact that the life, taken as a whole, of one who has

a disability is also thereby disadvantaged "on balance." As we have been at pains to show in this work, a BPS account of disability is able to accommodate this important distinction.

C. Implications for the disability rights (DR) movement and the relationship between the disabled and society

With respect to the concerns raised by the disability rights (DR) movement—which, it must be emphasized, this work is not in any way intended to belittle or otherwise undermine—there is an important implication deriving from this work's contention that there is no necessary entailment between conceptualizations of disability, on the one hand, and specific social justice claims on the other. The (perhaps surprising) implication here is that rather than *undermining* the DR position, an appreciation of this reality can in fact have the salutary effect of genuinely *leveling* the proverbial "playing field" for persons with disabilities. This is because while the aforementioned contention does have the effect of limiting any *a priori* claims to social accommodation and/or social resources—each putative "social justice" claim must be evaluated individually on its own merits—this restriction *applies equally to all parties* involved in negotiating various social arrangements that impact the lives of those with disabilities. Consequently, just as there can be no *a priori* positive claims to social accommodation or resources, so there can be no *a priori* arguments *against* the legitimacy of such claims. If a "level playing field" is truly the objective in such negotiations, then it would appear to be the case that, by breaking the alleged necessary connection between conceptualizations of disabilities and social justice claims, a BPS approach as outlined in this work is helpful in securing a theoretical foundation for such a level starting point.

This implication follows as well from what we have said about the relationship between disability and "opportunity." As our discussion has shown, from an ontological point of view disability does involve real loss. However, because disability also involves a complex interplay of biological/psychological/social factors, that ontological loss does not necessarily entail *overall* loss of opportunity. If this is correct, then DR advocates like Amundson are correct to reject the alleged *necessary* connection between disability and limitation of opportunity. This will not settle the issue definitively, but it does place the issue back within the domain of social-political negotiation, rather than being a matter of conceptual entailment (i.e., by definition, disability =

loss of opportunity). The end result, then, is that claims to accommodation, social changes, etc.—as well as *opposition* to such claims—will be a matter of case-by-case evaluation and sociopolitical negotiation. In the end, this may leave both sides to the debate unsatisfied—there are no definite, absolute entailments in either direction—but this seems to be the import of this work's conceptual analysis.

IV. REMAINING QUESTIONS AND AREAS FOR FURTHER RESEARCH

This work is conceived as the first stage in a larger, three-stage research program. The first stage asks the question "*what is disability?*" and takes place primarily at the level of conceptual analysis, considering various models and definitions of disability with a view toward arriving at an adequate theoretical account of the phenomenon of disability. The next stage considers the question "*What is the relationship between concepts/models of disability and theories of social justice/equality?*" We have argued in this work that that relationship is not a *necessary* one; nevertheless, this does not mean that there is *no* relationship at all between these two domains. So, the next stage of the larger research project is to connect up our theoretical insights regarding the concept of disability to theories of social justice and equality, with a view toward understanding how these two conceptual domains relate to and interact with one another. Finally, stage 3 of this research program will seek to apply the insights gleaned from the theoretical investigations of the first two stages in the context of specific ethical controversies, particularly in the realm of bioethics but also with respect to other questions arising in social and political philosophy more generally. We can summarize these three stages as follows:

(1) Stage 1: What is disability? (Conceptual analysis, models, etc.)

(2) Stage 2: What is the relationship between concepts/models of disability and theories of social justice/equality?

(3) Stage 3: What are the practical implications of (1) and (2), especially in the field of bioethics?

As we have noted already, this project has focused almost exclusively on the first of these three stages in the larger research project; a complete development of stages 2 and 3 has been explicitly bracketed and deferred to subsequent work. Given this focus, many questions have

been deliberately left unanswered, particularly those that might arise in the second and third stages. Nevertheless, if this present work has been successful, we have shown that a biopsychosocial approach to disability provides us with fruitful theoretical and conceptual resources for approaching the second and third stages of this larger research program.

WORKS CITED

Albrecht, G. L. (2006). *Encyclopedia of Disability.* Thousand Oaks, CA: Sage Publications, Inc.

Albrecht, G. L., Seelman, K. D., & Bury, M. (Eds.). (2001). *Handbook of Disability Studies.* Thousand Oaks, CA: Sage Publications, Inc.

Allen, B. (2005). Foucault's Nominalism. In S. Tremain (Ed.), *Foucault and the Government of Disability* (pp. 93-107). Ann Arbor, MI: The University of Michigan Press.

Altman, A. (2003). Civil Rights. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy* [Online]. Available: http://plato.stanford.edu/entries/civil-rights/.

Altman, B. M. (2001). Disability Definitions, Models, Classification Schemes, and Applications. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 97-122). Thousand Oaks, CA: Sage Publications, Inc.

AMA Committee on Medical Rating of Physical Impairment. (1958). Guides to the Evaluation of Permanent Impairment. *Journal of the American Medical Association, 9,* 3.

Americans with Disabilities Act. (1990). Public Law 101-336—July 26, 1990, beginning at 42 USC 12101 (104 Stat. 321).

Amundson, R. (1992). Disability, Handicap, and the Environment. *Journal of Social Philosophy, 23,* 114-118.

Amundson, R. (2005). Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics. In D. Wasserman, J. Bickenbach, & R. Wachbroit (Eds.), *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, Cambridge Series in Philosophy and Public Policy (pp. 101-124). New York, NY: Cambridge University Press.

Amundson, R. (2009). Disability Rights: Do We Really Mean It? In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 169-182). Dordrecht, The Netherlands: Springer.

Amundson, R., & Tresky, S. (2007). On a Bioethical Challenge to Disability Rights. *Journal of Medicine and Philosophy*, *32*(6), 541-561.

Anon. (2005). Final Discussion: How to Overcome the Barriers. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. 217-223). Oxford, UK; New York, NY: Oxford University Press.

Aristotle. *Nicomachean Ethics.*

Arneson, R. (2002a). Egalitarianism. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy* [Online]. Available: http://plato.stanford.edu/entries/egalitarianism/.

Arneson, R. (2002b). Equality of Opportunity. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy* [Online]. Available: http://plato.stanford.edu/entries/equal-opportunity/

Asch, A. (1989). Reproductive Technology and Disability. In S. Cohen & N. Taub (Eds.), *Reproductive Laws for the 1990's* (pp 69-124). Clifton, N.J.: Humana Press.

Asch, A. (2000). Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements. In E. Parens & A. Asch. (eds.), *Prenatal Testing and Disability Rights* (pp. 234-250). Washington, D.C.: Georgetown University Press.

Asch, A., & Wasserman, D. (2005). Where Is the Sin in Synecdoche? Prenatal Testing and the Parent-Child Relationship. In D. Wasserman, J. Bickenbach, & R. Wachbroit (Eds.), *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, Cambridge Studies in Philosophy and Public Policy (pp. 172-216). New York: Cambridge University Press.

Asch, A., & Wasserman, D. (2006). Bioethics. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 165-171). Thousand Oaks, CA: Sage Publications, Inc.

Audi, R. (Ed.) (1995). *The Cambridge Dictionary of Philosophy.* Cambridge, UK; New York, NY: Cambridge University Press.

Bach, J. R., & Tilton, M. C. (1994). Life Satisfaction and Well-Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia. *Archives of Physical Medicine and Rehabilitation*, *75*(6), 626-632.

Bahan, B., & Parish, E. (2006). Deaf Culture. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 349-353). Thousand Oaks, CA: Sage Publications, Inc.

Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge, UK and Malden, MA: Polity Press and Blackwell Publishers.

Barnes, C., Oliver, M., & Barton, L. (2002). *Disability Studies Today*. Cambridge, UK; Malden, MA: Polity Press; Blackwell Publishers.

Barsalou, L. W. (1992). Frames, Concepts, and Conceptual Fields. In A. Lehrer & E. F. Kittay (Eds.), *Frames, Fields and Contrasts: New Essays in Semantic and Lexical Organization* (pp. 21-74). Hillsdale, New Jersey: Lawrence Erlbaum.

Bavelier, D., Tomann, A., Hutton, C., Mitchell, T., Corina, D., Liu, G., & Neville, H. (2000). Visual Attention to the Periphery is Enhanced in Congenitally Deaf Individuals. *The Journal of Neuroscience, 20* [Online]. Available: http://www.jneurosci.org/cgi/content/full/20/17/RC93.

Berbrier, M. (2002). Making Minorities: Cultural Space, Stigma Transformation Frames, and the Categorical Status Claims of Deaf, Gay, and White Supremacist Activists in Late Twentieth Century America. *Sociological Forum, 17*(4), 553-591.

Bickenbach, J. (1993). *Physical Disability and Social Policy.* Toronto: University of Toronto Press.

Bickenbach, J. E. (2006). International Classification of Functioning, Disability, and Health (ICF/ICIDH). In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 966-970). Thousand Oaks, CA: Sage Publications, Inc.

Boer, S. E. (1974). Cluster-Concepts and Sufficiency Definitions. *Philosophical Studies, 26*, 119-125.

Boorse, C. (1975). On the Distinction Between Disease and Illness. *Philosophy and Public Affairs, 5,* 49-68.

Boorse, C. (2009). Disability and Medical Theory. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 55-88). Dordrecht, The Netherlands: Springer.

Bourdieu, P. (1990 [1980]). Structures, Habitus, Practices. In *The Logic of Practice* (pp. 52- 65). Stanford: Stanford University Press.

Buchanan, A., Brock, D. W., Daniels, N., & Wikler, D. (2000). *From Chance to Choice: Genetics and Justice.* Cambridge, UK; New York, NY: Cambridge University Press.

Burgdorf, Jr., R. L. (2006). Americans with Disabilities Act of 1990 (US). In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 93-100). Thousand Oaks, CA: Sage Publications, Inc.

Bury, M. (2000). A Comment on the ICIDH-2. *Disability & Society, 15*, 1073-1077.

Cameron, P., Titus, D. G., Kostin, J., & Kostin, M. (1973). The Life Satisfaction of Nonnormal Persons. *Journal of Consulting and Clinical Psychology, 41*(2), 207-214.

Caplan, A. L., Engelhardt, Jr., H. T., & McCartney, J. J. (Eds.). (1981). *Concepts of Health and Disease: Interdisciplinary Perspectives.* Reading, MA: Addison-Wesley Pub.

Cartwright, S. A. (1851/1981). Report on the Diseases and Physical Peculiarities of the Negro Race. *The New Orleans Medical and Surgical Journal* (May), 691-715. Reprinted in A. L. Caplan, H. T. Engelhardt, Jr., & J. J. McCartney (Eds.), *Concepts of Health and Disease: Interdisciplinary Perspectives* (pp. 305-326). Reading, MA: Addison-Wesley Pub.

Centre for Universal Design. (1997). *The Principles of Universal Design* [Online]. Available: http://www.design.ncsu.edu/cud/univ_design/principles/udprinciples.htm

Cleese, J. (2006). *Profile: John Cleese* (Interviewer M. Bragg). Ovation Channel. Broadcast December 18, 2006, copyright 1986.

Clouser, K. D., Culver, C. M., & Gert, B. (1997). Malady. In J. M. Humber & R. F. Almeder (Eds.), *What is Disease?*, Biomedical Ethics Reviews (pp. 173-217). Totawa, NJ: Humana Press.

Coleman, L. M. (1997). Stigma: An Enigma Demystified. In L. Davis (Ed.), *The Disability Studies Reader* (pp. 216-231). New York and London: Routledge.

Committee on a National Agenda for the Prevention of Disabilities, Institute of Medicine (IOM). (1991). *Disability in America: Toward a National Agenda for Prevention.* (A. M. Pope & A. R. Tarlov, Eds.). Washington, D.C.: National Academy Press.

Committee on Assessing Rehabilitation Science and Engineering, Institute of Medicine (IOM). (1997). *Enabling America: Assessing the Role of Rehabilitation Science and Engineering.* (E. N. Brandt & A. M. Pope, Eds.). Washington, D.C.: National Academy Press.

Committee on Disability in America, Board on Health Sciences Policy, Institute of Medicine of the National Academies (IOM). (2007). *The Future of Disability in America.* (M. J. Field & Jette, Eds.). Washington, D.C.: The National Academies Press.

Cooper, D. E. (1972). Definitions and 'Clusters'. *Mind*, New Series, *81*(324), 495-503.

Cooper, R. (2007). 'Can it be a Good Thing to be Deaf?' *Journal of Medicine and Philosophy, 32,* 563-583.

Cushman, L. A., & Dijkers, M. P. (1990). Depressed Mood in Spinal Cord Injured Parents: Staff Perceptions and Patient Realities. *Archives of Physical Medicine and Rehabilitation*, *71*(3), 191-196.

D'Amico, R. (1995). Is Disease a Natural Kind? *Journal of Medicine and Philosophy*, *20*, 551-569.

Daniels, N. (1985). *Just Health Care.* Studies in Philosophy and Health Policy. Cambridge, UK; New York, NY: Cambridge University Press.

Daniels, N. (1990). Equality of What: Welfare, Resources, or Capabilities? *Philosophy and Phenomenological Research*, *50*, 273-296.

Daniels, N. (2007). *Just Health: Meeting Health Needs Fairly.* Cambridge, UK and New York, NY: Cambridge University Press.

Davis, L. (Ed.). (1997). *The Disability Studies Reader.* New York and London: Routledge.

Devlieger, P. (1995). Why Disability? The Cultural Understanding of Disability in an African Society. In B. Ingstadt & S. R. Whyte (Eds.), *Disability and Culture* (pp. 94-105). Berkeley, CA: University of California Press.

DiMaggio, P. (1997). Culture and Cognition. *Annual Review of Sociology*, *23*, 263-287.

Douglas, M. (1986). *How Institutions Think.* Syracuse, NY: Syracuse University Press.

DPI. (1982). *Proceedings of the First World Congress.* Singapore: Disabled People's International.

Dworkin, R. (1981a). What is Equality? Part 1: Equality of Welfare. *Philosophy and Public Affairs*, *10*(3), 185-246.

Dworkin, R. (1981b). What is Equality? Part 2: Equality of Resources. *Philosophy and Public Affairs*, *10*(4), 283-345.

Dworkin, R. (2000). *Sovereign Virtue: The Theory and Practice of Equality*. Cambridge, MA; London, UK: Harvard University Press.

Dworkin, R. (2000a). Playing God: Genes, Clones, and Luck. In *Sovereign Virtue: The Theory and Practice of Equality* (pp. 427-452). Cambridge, MA; London, UK: Harvard University Press.

Dworkin, R. (2000b). Equality and Capability. In *Sovereign Virtue: The Theory and Practice of Equality* (pp. 285-303). Cambridge, MA; London, UK: Harvard University Press.

Dworkin, R. (2000c). Equality of Resources. In *Sovereign Virtue: The Theory and Practice of Equality* (pp. 65-119). Cambridge, MA; London, UK: Harvard University Press.

Dworkin, R. (2000d). Equality of Welfare. In *Sovereign Virtue: The Theory and Practice of Equality* (pp. 11-64). Cambridge, MA; London, UK: Harvard University Press.

Dworkin, R. (2000e). Introduction: Does Equality Matter? In *Sovereign Virtue: The Theory and Practice of Equality* (pp. 1-7). Cambridge, MA; London, UK: Harvard University Press.

Eareckson Tada, J. & Jensen, S. (2006). *Through the Roof,* rev. ed. Manual published by Joni and Friends International Disability Center. Orig. pub. 1995.

Edwards, S. D. (1997). Dismantling the disability/handicap distinction. *The Journal of Medicine and Philosophy*, *22*(6), 589-606.

Eiseland, Nancy L. (1994). *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville: Abingdon Press.

Eisenberg, M. G., & Saltz, C. C. (1991). Quality of Life Among Aging Spinal Cord Injured Persons: Long Term Rehabilitation Outcomes. *Paraplegia*, *29*, 514-520.

Elshtain, J. B. (2009). Neither Victims Nor Heroes: Reflections from a Polio Person. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 242-250). Dordrecht, The Netherlands: Springer.

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*, 129-136.

Engel, G. L. (1981). The Need for a New Medical Model: A Challenge for Biomedicine. In Caplan, A. L., Engelhardt, H. T., Jr., & McCartney, J. J. (Eds.), *Concepts of Health and Disease:*

Interdisciplinary Perspectives (pp. 589-607). Reading, MA: Addison-Wesley Pub. Originally published in *Science, 196* (April 8, 1977), 129-136.

Engelhardt, Jr., H. T. (1976). Ideology and Etiology. *Journal of Medicine and Philosophy*, *1*(3), 256-268.

Engelhardt, Jr., H. T. (1981). The Disease of Masturbation: Values and the Concept of Disease. In A. L. Caplan, H. T. Engelhardt, Jr., & J. J. McCartney (Eds.), *Concepts of Health and Disease: Interdisciplinary Perspectives* (pp. 267-280). Reading, MA: Addison-Wesley Publishing.

Engelhardt, Jr., H. T. (1996). *The Foundations of Bioethics* (2nd ed.). New York: Oxford University Press.

Engelhardt, Jr., H. T. (2009). The Unfair and the Unfortunate: Some Brief Critical Reflections on Secular Moral Claim Rights for the Disabled. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability* (pp. 229-237). Dordrecht, The Netherlands: Springer.

Evans, E. (2010). The Meaning of (Gestating) Life [Book review of *Embodying Culture: Pregnancy in Japan and Israel*, by Ivry Tsipy (Rutgers Univ. Press, 2009)]. *Books & Culture: A Christian Review*, *May/June*, 11-12.

Faden, R. (1994). Reproductive Genetic Testing, Prevention, and the Ethics of Mothering. In E. Thomson & K. Rothenberg (Eds.), *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* (pp. 88-98). Columbus, OH: Ohio State University Press.

Farr R. M., & Moscovici, S. (1984). *Social Representations*. Cambridge: Cambridge University Press.

Field, S. (1994). *Screenplay: The Foundations of Screenwriting*. New York: Dell Publishing.

Fleck, L. (1979). *Genesis and Development of a Scientific Fact*. (T. J. Trenn & R. K. Merton, Eds.). Chicago and London: The University of Chicago Press.

Foucault, M. (1994 [1963]). *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Vintage.

Gamson, J. (1995). Must Identity Movements Self-Destruct? A Queer Dilemma. *Social Problems*, 42, 390-407.

Gamson, W. A. (1992). *Talking Politics*. New York: Cambridge University Press.

Garland, R. (1995). *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World*. Ithaca, NY: Cornell University Press.

Gaus, G., & Courtland, S. D. (2011). Liberalism. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Spring 2011 Edition) [Online]. Available: http://plato.stanford.edu/archives/spr2011/entries/liberalism/.

Gilbert, D. T. (1991). How Mental Systems Believe. *American Journal of Psychology*, *46*,107-119.

Gleason, P. (1991). Minorities (Almost) All: The Minority Concept in American Social Thought. *American Quarterly*, *43*(3), 392-424.

Goffman, E. (1986 [1963]). Stigma: Notes on the Management of Spoiled Identity. Touchstone/Simon & Schuster.

Goffman, E. (1997). Selections from *Stigma*. In L. Davis, (Ed.), *The Disability Studies Reader* (pp. 203-215). New York and London: Routledge.

Gosepath, S. (2006). Equality. In Edward N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* [Online]. Available: http://plato.stanford.edu/entries/equality/.

Gwaltney, J. (1970). *The Thrice Shy: Cultural Accommodation to Blindness and Other Disasters in a Mexican Community*. New York, NY; London, UK: Columbia University Press.

Hauerwas, S. (2008). The Politics of Gentleness. In S. Hauerwas & J. Vanier, *Living Gently in a Violent World: The Prophetic Witness of Weakness*, Resources for Reconciliation (pp. 77-99). Downers Grove, IL: InterVarsity Press.

Hughes, B. (2002). Disability and the Body. In C. Barnes, M. Oliver, & L. Barton (Eds.), *Disability Studies Today*. Cambridge, UK; Malden, MA: Polity Press; Blackwell Publishers.

Hursthouse, R. (2003). Virtue Ethics. In Edward N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy (Fall 2003 Edition)* [Online]. Available: http://plato.stanford.edu/archives/fall2003/entries/ethics-virtue/

Illingworth, P., & Parmet, W. E. (2000). Positively Disabled: The Relationship between the Definition of Disability and Rights under the ADA. In *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (pp. 3-17). London, UK; New York, NY: Routledge.

International League of Societies for Persons with Mental Handicap. (1994). *Just Technology? From Principles to Practice in Bio-ethical Issues*. Brussels: Roeher Institute.

Ivry, T. (2009). *Embodying Culture: Pregnancy in Japan and Israel*. Rutgers University Press.

Jacobs, A. (2008). *Original Sin: A Cultural History.* New York: HarperOne.

Jette, A. M. (1997). Disablement Outcomes in Geriatric Rehabilitation. *Medical Care, 35,* JS28-37.

Juengst, E. T. (2004). Concepts of Disease after the Human Genome Project. In A. L. Caplan, J. J. McCartney, & D. A. Sisti (Eds.), *Health, Disease, and Illness: Concepts in Medicine* (pp. 243-262). Washington, D.C.: Georgetown University Press.

Kent, D. (2000). Somewhere a Mockingbird. In E. Parens & A. Asch (Eds.), *Prenatal Testing and Disability Rights*, Hastings Center Studies in Ethics (pp. 57-63). Washington, D.C.: Georgetown University Press.

Kuczewski, M. (2001). Disability: An Agenda for Bioethics. *American Journal of Bioethics*, *1*(3), 36-44.

Lacey, A. R. (1986a). *A Dictionary of Philosophy,* 2nd ed. London, UK; New York, NY: Routledge.

Lacey, A. R. (1986b). Epistemology. In A. R. Lacey (Ed.), *A Dictionary of Philosophy* (2nd ed., pp. 63-65). London, UK; New York, NY: Routledge.

Lacey, A. R. (1986c). Metaphysics. In A. R. Lacey (Ed.), *A Dictionary of Philosophy* (2nd ed., pp. 143-146). London, UK; New York, NY: Routledge.

Lausanne Committee on World Evangelization. (2004). Hidden and Forgotten People – Ministry Among People with Disabilities. Lausanne Occasional Paper No. 35B, Produced by the Issue Group on this topic at the 2004 Forum for World Evangelization hosted by the Lausanne Committee for World Evangelization, in Pattaya, Thailand, September 29 to

October 5, 2004 ("A New Vision, a New Heart, a Renewed Call") [Online]. Available: http://www.lausanne.org/documents/2004forum/LOP35B_IG13.pdf.

Lemos, N. M. (1995). Value Theory. In R. Audi (Ed.), *The Cambridge Dictionary of Philosophy* (pp. 830-831). Cambridge, UK; New York, NY: Cambridge University Press.

Macintyre, A. (1999). *Dependent Rational Animals: Why Human Beings Need the Virtues*. The Paul Carus Lectures. Chicago, IL; La Salle, IL: Open Court.

Malik, J. A., & Koot, H. M. (2009). Explaining the Adjustment of Adolescents with Type 1 Diabetes. *Diabetes Care, 32(5),* 774-779.

Malmgren, H. (2005). The Theoretical Basis of the Biopsychosocial Model. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. 20-38). Oxford, UK; New York, NY: Oxford University Press.

Margolis, E., & Laurence, S. (2006). Concepts. In Edward N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* [Online]. Available: http://plato.stanford.edu/entries/concepts/.

Markus, H. R., & Kitayama, S. (1994). The Cultural Construction of Self and Emotion: Implications for Social Behavior. In S. Kitayama & H. R. Markus (Eds.), *Emotion and Culture: Empirical Studies of Mutual Influence* (pp. 89-130). Washington, D.C.: American Psychological Association.

Markus, H. R., Kitayama, S., & Heiman, R. (1996). Culture and 'Basic' Psychological Principles. In E. T. Higgins & A. W. Kruglanski (Eds.), *Social Psychology: Handbook of Basic Principles*. New York: Guilford.

Martin, J. (1992). *Cultures in Organizations: Three Perspectives*. New York: Oxford University Press.

McMahan, J. (2005). Preventing the Existence of People with Disabilities. In D. Wasserman, J. Bickenbach, & R. Wachbroit (Eds.), *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, Cambridge Studies in Philosophy and Public Policy (pp. 142-171). New York, NY: Cambridge University Press.

Merriam, G. (2009). Rehabilitating Aristotle: A Virtue Ethics Approach to Disability and Human Flourishing. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 133-151). Dordrecht, The Netherlands: Springer.

Merton, R. K. (1957). *Social Theory and Social Structure*. New York: Free Press.

Milburn, M. A. (1987). Ideological Self-schemata and Schematically Induced Attitude Consistency. *Journal of Experimental Social Psychology, 23*, 383-398.

Miller, D. T., & Prentice, D. A. (1996). The Construction of Social Norms and Standards. In E. T. Higgins & A. W. Kruglanski (Eds.), *Social Psychology: Handbook of Basic Principles*. (pp. 799-829). New York: Guilford.

Morris, J. (1991). *Pride Against Prejudice*. Philadelphia, PA; Gabriola Island, B.C.: New Society Publishers.

Nagi, S. Z. (1991). Disability Concepts Revisited: Implications for Prevention. In A. M. Pope & A. R. Tarlov (Eds.), *Disability in America: Toward a National Agenda for Prevention* (pp. 309-327). Washington, D.C.: National Academy Press.

National Digital Archives of Datasets (NDAD). (1996). Data for Health Authorities Boundaries at April 1996 (PHO-A4.1B). Down's Syndrome: Diagnoses and Outcomes in the Period 1994 to 1996. (Data from the National Down Syndrome Cytogenic Register.) [Online]. Available: http://ndad.ulcc.ac.uk/.

Noelle-Neumann, E. (1993 [1980]). T*he Spiral of Silence: Public Opinion—Our Social Skin*. Chicago: University of Chicago Press.

Nordenfelt, L. (1997). The importance of a disability/handicap distinction. *The Journal of Medicine and Philosophy, 22*, 607-622.

Nordenfelt, L. (2000). *Action, Ability, and Health: Essays in the Philosophy of Action and Welfare*. International Library of Ethics, Law, and the New Medicine. Dordrecht, The Netherlands; Boston, MA; London, UK: Kluwer Academic Publishers.

Nordenfelt, L. (2001). *Health, Science, and Ordinary Language*. Amsterdam: Rodopi Publishers.

Nordenfelt, L. (2009). Ability, Competence, and Qualification: Fundamental Concepts in the Philosophy of Disability. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on*

Disability, Philosophy and Medicine (Vol. 104, pp. 37-54). Dordrecht, The Netherlands: Springer.

nosography. (n.d.). *Merriam-Webster's Medical Dictionary* [Online]. Retrieved January 16, 2011, from Dictionary.com website: http://dictionary.reference.com/browse/nosography

nosography. (n.d.). *The American Heritage® Stedman's Medical Dictionary* [Online]. Retrieved January 16, 2011, from Dictionary.com website: http://dictionary.reference.com/browse/nosography

Nozick, R. (1974). *Anarchy, State, and Utopia.* New York: Basic Books.

Nussbaum, M. C. (2007). *Frontiers of Justice: Disability, Nationality, Species Membership.* Cambridge, MA and London, UK: Belknap Press/Harvard University Press.

Oliver, M. (1990). *The Politics of Disablement: A Sociological Approach.* New York: St. Martin's Press.

Padden, C., & Humphries, T. (1988). *Deaf in America: Voices from a Culture.* Cambridge, MA: Harvard University Press.

Papsin, B. C. & Gordon, K. A. (2007). Cochlear Implants for Children with Severe-to-Profound Hearing Loss. *New England Journal of Medicine*, *357*(23), 2380-2387.

Parens, E. & Asch, A. (Eds.). (2000a). *Prenatal Testing and Disability Rights.* Washington, D.C.: Georgetown University Press.

Parens, E., & Asch, A. (2000b). The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations. In E. Parens & A. Asch (Eds.), *Prenatal Testing and Disability Rights*, Hastings Center Studies in Ethics (pp. 3-43). Washington, D.C.: Georgetown University Press.

Parfit, D. (1997). Equality and Priority. *Ratio*, *10*(3), 202-221.

Parsons, K. P. (1973). Three Concepts of Clusters. *Philosophy and Phenomenological Research*, *33*(4), 514-523.

Peters, S. J. (2006). Disability Culture. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 412-420). Thousand Oaks, CA: Sage Publications, Inc.

Plato. *Protagoras.*

Ponten, M. J. (2004). *Taboo and Disability.* Unpublished training manual for Mephibosheth Ministries.

Purdy, L. M. (2009). Too Late to Matter? Preventing the Birth of Infants at Risk for Adult-Onset Disease or Disability. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability* (pp. 109-122). Dordrecht, The Netherlands: Springer.

Rainville, J., Pransky, G., Indahl, A., and Mayer, E. K. (2005). The Physician as Disability Advisor for patients with Musculoskeletal Complaints. *Spine, 30(22),* 2579-2584 (Nov. 15).

Ralston, D. C., & Ho, J. (2007a). Disability, Humanity, and Personhood: A Survey of Moral Concepts. *Journal of Medicine and Philosophy*, *32*, 619-633.

Ralston, D. C., & Ho, J. (2007b). Introduction. *Journal of Medicine and Philosophy*, *32*, 537-539.

Ralston, D. C., & Ho, J. (2009a). Introduction: Philosophical Reflections on Disability. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 1-16). Dordrecht, The Netherlands: Springer.

Ralston, D. C., & Ho, J. (Eds.). (2009b). *Philosophical Reflections on Disability.* Philosophy and Medicine (Vol. 104). Dordrecht, The Netherlands: Springer.

Reinders, H. S. (2000). *Future of the Disabled in Liberal Society: An Ethical Analysis.* Sound Bend, IN: University of Notre Dame Press.

Reinders, H. S. (2006). Human Dignity in the Absence of Agency. In R. K. Soulen & L. Woodhead (Eds.), *God and Human Dignity* (pp. 121-139). Grand Rapids, MI; Cambridge, UK: Eerdmans.

Reinders, H. S. (2008). *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics.* Grand Rapids, MI: Eerdmans.

Reznek, L. (1987). *The Nature of Disease.* New York: Routledge and Kegan Paul.

Reznek, L. (1995). Dis-Ease about Kinds: Reply to D'Amico. *Journal of Medicine and Philosophy*, *20*, 571-584.

Scheer, J. & Groce, N. (1998). Impairment as a Human Constraint: Cross-Cultural and Historical Perspectives on Variation, *Journal of Social Issues, 44,* 23-27.

Schudson, M. (1989). How Culture Works: Perspectives from Media Studies on the Efficacy of Symbols. *Theory and Society, 18*, 153-180.

Schwartz, J. A., Siegal, C. D., Waterstone, M., Hill, E., & Peter Blanck. (2006). Disability Policy: United States. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 468-476). Thousand Oaks, CA: Sage Publications, Inc.

Scotch, R. K. (1989). Politics and Policy in the History of the Disability Rights Movement. *The Milbank Quarterly, 67*, 380-400.

Sedikides, C., & Skowronski, J. J. (1991). The Law of Cognitive Structure Activation. *Psychological Inquiry, 2*, 169-184.

Sewell, W. H., Jr. (1992). A Theory of Structure: Duality, Agency, and Transformation. *American Journal of Sociology, 98*, 1-29

Seyle, H. (1956). *The Stress of Life.* New York: McGraw-Hill.

Shakespeare, T. (2006). *Disability Rights and Wrongs.* London and New York: Routledge.

Shakespeare, T., Bickenbach, J. E., Pfeiffer, D., & Watson, N. (2006). Models. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 1101-1108). Thousand Oaks, CA: Sage Publications, Inc.

Sher, G. (1989). *Desert.* Princeton, NJ: Princeton University Press.

Shestak, J. J. (1998). The Philosophic Foundations of Human Rights. *Human Rights Quarterly, 20,* 201-234.

Shorter, E. (2005). The History of the Biopsychosocial Approach in Medicine: Before and after Engel. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. 1-19). Oxford, UK; New York, NY: Oxford University Press.

Shuttleworth, R. P., & Kasnitz, D. (2006). Cultural Context of Disability. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 330-337). Thousand Oaks, CA: Sage Publications, Inc.

Silvers, A. (1998). Formal Justice. In A. Silvers, D. Wasserman, & M. B. Mahowald (Eds.), *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (pp. 13-145). Lanham, MD; Oxford, UK: Rowman & Littlefield Publishers, Inc.

Silvers, A. (2003). On the Possibility and Desirability of Constructing a Neutral Conception of Disability. *Theoretical Medicine*, *24*, 471-487.

Silvers, A. (2009). An Essay on Modeling: The Social Model of Disability. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability*, Philosophy and Medicine (Vol. 104, pp. 19-36). Dordrecht, The Netherlands: Springer.

Silvers, A., Wasserman, D., & Mahowald, M. B. (Eds.). (1998). *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy.*. Lanham, MD; Oxford, UK: Rowman & Littlefield Publishers, Inc.

Smith, W. J. (2000). Is Bioethics Ethical? *The Weekly Standard* (April 3) [Online]. Available: http://www.petersnet.net/browse/3446.htm.

Sniderman, P. M, & Piazza, T. (1993). *The Scar of Race*. Cambridge, MA: Harvard University Press.

Snyder, S. L. (2006). Disability Studies. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 478-490). Thousand Oaks, CA: Sage Publications, Inc.

Snyder, S. L., & Mitchell, D. T. (2006). *Cultural Locations of Disability*. Chicago: University of Chicago Press.

Sober, E. (1980). Evolution, Population Thinking, and Essentialism. *Philosophy of Science*, *47*(3), 350-383.

Sober, E. (1995). Natural Kind. In J. Kim & E. Sosa (Eds.), *A Companion to Metaphysics* (pp. 345-346). Cambridge, MA; London, UK: Blackwell.

Stangl, R. (2010). Selective Terminations and Respect for the Disabled. *Journal of Medicine and Philosophy*, *35*, 32-45.

Steinbock, B. (2000). Disability, Prenatal Testing, and Selective Abortion. In E. Parens & A. Asch (Eds.), *Prenatal Testing and Disability Rights*, Hastings Center Studies in Ethics (pp. 108-123). Washington, D.C.: Georgetown University Press.

Stensman, R. (1994). Adjustment to Traumatic Spinal Cord Injury. A Longitudinal Study of Self-Reported Quality of Life. *Paraplegia*, *32*, 416-422.

Stone, D. (1984). *The Disabled State.* Philadelphia, PA: Temple University Press.

Storey, J. (1998). *Cultural Theory and Popular Culture: A Reader.* Athens, GA: University of Georgia Press.

Sulmasy, D. P. (2009). Dignity, Disability, Difference, and Rights. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability* (pp. 183-198). Dordrecht, The Netherlands: Springer.

Swidler, A. (1986). Culture in Action: Symbols and Strategies. *American Sociological Review, 51*, pp. 273-286.

Swidler, A. (1997). *Talk of Love: How Americans Use Their Culture.* Chicago: University of Chicago Press.

Szasz, T. (1961). *The Myth of Mental Illness.* New York: Harper & Row.

Tännsjö, T. (2009). Utilitarianism, Disability, and Society. In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability* (pp. 91-108). Dordrecht, The Netherlands: Springer.

Tarlov, Alvin R. (1991). Preface. In A. M. Pope & A. R. Tarlov (Eds.), *Disability in America: Toward a National Agenda for Prevention* (pp. v-viii). Washington, D.C.: National Academy Press.

Toombs, S. Kay. (1992). *The Meaning of Illness.* Philosophy and Medicine (Vol. 42). Dordrecht, The Netherlands: Kluwer Academic Publishers.

Tucker, B. P. (1997). The ADA and Deaf Culture: Contrasting Precepts, Conflicting Results. *Annals of the American Academy of Political and Social Science*, *549*, 24-36.

Turner, B. S. (Ed.). (1999). *The Talcott Parsons Reader.* Malden, MA; Oxford, UK: Wiley-Blackwell.

United Nations General Assembly. (2006). Convention on the Rights of Persons with Disbilities [Online]. Available: http://www.un.org/disabilities/.

UPIAS. (1976). *Fundamental Principles of Disability.* London: Union of the Physically Impaired Against Segregation.

Vallentyne, P. (2010). Libertarianism. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy (Fall 2010 Edition)* [Online]. Available: http://plato.stanford.edu/archives/fall2010/entries/libertarianism/.

Veatch, R. (1981). The Medical Model: Its Nature and Problems. In A. L. Caplan, H. T. Engelhardt, Jr., & J. J. McCartney (Eds.), *Concepts of Health and Disease: Interdisciplinary Perspectives* (pp. 523-544). Reading, MA: Addison-Wesley Publishing Company.

Veatch, R. M. (1986). *The Foundations of Justice: Why the Retarded and the Rest of us Have Claims to Equality.* Oxford and New York: Oxford University Press.

Verbrugge, L. M., & Jette, A. M. (1994). The Disablement Process. *Social Science & Medicine*, *38*(1), 1-14.

Von Korff, M. (2005). Fear and Depression as Remediable Causes of Disability in Common Medical Conditions in Primary Care. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. 117-131). Oxford, UK; New York, NY: Oxford University Press.

Wasserman, D. (1998). Distributive Justice. In A. Silvers, D. Wasserman, & M. B. Mahowald (Eds.), *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (pp. 147-207). Lanham, MD; Oxford, UK: Rowman & Littlefield Publishers, Inc.

Wasserman, D. (2001). Philosophical Issues in the Definition and Social Response to Disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 219-251). Thousand Oaks, CA: Sage Publications, Inc.

Wasserman, D., Bickenbach, J., & Wachbroit, R. (Eds.). (2005). *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability.* Cambridge Studies in Philosophy and Public Policy. New York: Cambridge University Press.

Waterstone, M., Siegal, C. D., Hill, E., & Blanck, P. (2006). Disability Law: United States. In G. L. Albrecht (Ed.), *Encyclopedia of Disability* (pp. 452-461). Thousand Oaks, CA: Sage Publications, Inc.

Wessely, S. (2005). Foreword. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. vii-xiv). Oxford, UK; New York, NY: Oxford University Press.

White, P. (2005a). Beyond the Biomedical to the Biopsychosocial: Integrated Medicine. In P. White (Ed.), *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness* (pp. 225-234). Oxford, UK; New York, NY: Oxford University Press.

White, P. (Ed.). (2005b). *Biopsychosocial Medicine: An Integrated Approach to Understanding Illness*. Oxford, UK; New York, NY: Oxford University Press.

William Osler – Biography [Online]. (n.d.). Available: http://www.medicalarchives.jhmi.edu/osler/biography.htm.

Wirth, L. (1964). *On Cities and Social Life: Selected Papers*. A. J. Reiss, Jr. (Ed.). Chicago: University of Chicago Press.

Woodrich, F., & Patterson, J. B. (1983). Variables Related to Acceptance of Disability in Persons with Spinal Cord Injuries. *Journal of Rehabilitation*, (July-Sept.), 26-30.

World Health Organization (WHO). (1980). *International Classification of Impairments, Disabilities and Handicaps* [ICIDH]. Geneva: World Health Organization.

World Health Organization (WHO). (1990). *International Classification of Diseases*, tenth rev. [ICD-10]. Geneva: World Health Organization [Online]. Available: http://www.who.int/classifications/icd/en/

World Health Organization (WHO). (2001). *International Classification of Functioning, Disability, and Health,* Large print edition [ICF]. Geneva: World Health Organization.

World Health Organization. (n.d.). "WHO | International Classification of Functioning, Disability and Health (ICF)" [Online]. Available: Retrieved http://www.who.int/classifications/icf/en/.

Young, D. (1932). American Minority Peoples: A Study in Racial and Cultural Conflicts in the United States. New York: Harper and Brothers.